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**Against negative interpretation  
HIV/AIDS narratives in post-apartheid South Africa**

Wu, Charlotte

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***Against Negative Interpretation:  
HIV/AIDS Narratives  
in Post-Apartheid South Africa***

Charlotte Xiao Ou Wu

Submitted for Degree of PhD in 2018

English and Global Health Humanities

King's College London

## Table of Contents

<b>Abstract.....</b>	<b>4</b>
List of abbreviations and acronyms .....	5
List of Illustrations .....	7
Note on terminology and language .....	8
Acknowledgements .....	9
 <b>CHAPTER ONE – INTRODUCTION .....</b>	 <b>10</b>
AIDS as Metaphor, Africa as Metaphor .....	24
Decolonising African HIV/AIDS Discourses .....	35
HIV/AIDS in the South African context: A chronology .....	42
Under Apartheid and the colonial encounter (-1994) .....	42
Under President Nelson Mandela (1994 – 1999).....	47
Under President Thabo Mbeki (1999 – 2008) .....	54
Under President Jacob Zuma (2009 – 2018) and Cyril Ramaphosa (2018 – present).....	58
Conclusion and outline of chapters .....	62
 <b>CHAPTER TWO – READING THE MBEKI SCANDAL: NARRATIVE, CHARACTER AND MEMORY .....</b>	 <b>68</b>
Thabo Mbeki as Historical Protagonist.....	74
Searching for a Scapegoat.....	84
‘The Chief’: Contemporary portrayals in fiction and non-fiction .....	93
Conclusion .....	103
 <b>CHAPTER THREE – BREAKING THE SILENCE: PUBLIC AND HIDDEN TRANSCRIPTS .....</b>	 <b>106</b>
Public and hidden HIV/AIDS transcripts .....	111
Silence is Death: global implications in the context of HIV/AIDS .....	118
‘Blood on the Page’ or ‘An Eerie Silence’?.....	127
Conclusion .....	145

<b>CHAPTER FOUR – HIV/AIDS AND THE POST-APARTHEID CONDITION IN TWO CONTEMPORARY NOVELS .....</b>	<b>149</b>
Personal to political denial: Imraan Coovadia’s <i>Tales of the Metric System</i> .....	152
Treatment vs commodity: ART as sign of late capitalism.....	160
‘Last Life’: Phenomenology as style in Masande Ntshanga’s <i>The Reactive</i> .....	170
Conclusion .....	179
 <b>CHAPTER FIVE – HIV/AIDS AND THE BODY SOCIAL IN SOUTH AFRICAN NON-FICTION .....</b>	<b>182</b>
Ethnographies of treatment as national story-telling .....	189
Rival healthcare knowledges .....	198
Epistemic Gender Trouble .....	205
Conclusion .....	213
 <b>CHAPTER SIX – EPILOGUE .....</b>	<b>216</b>
 <b>Bibliography .....</b>	<b>227</b>

## **Abstract**

This thesis explores various narratives that have emerged in response to the HIV/AIDS pandemic in post-Apartheid South Africa. Building on the heightened interest in narrative and discourse as relating to health, power and society that has developed in the academy during recent decades, I bring these ideas together with schools of postcolonial thought to examine how the epidemic manifested as a social phenomenon in the post-apartheid context. In particular, I argue that both the macro-narrative of the HIV/AIDS epidemic and the intertwined narrative of the post-Apartheid nation remain incomplete unless certain pervasive discursive tropes are brought to the forefront of our reading. In the introductory chapter, I identify and engage the ‘prior discourse’ (Mbembe 2001) of Eurocentric readings and epistemic starting points which postcolonial theorists argue that writing from the postcolony is continually required to refute. South Africa presently has the highest burden of HIV/AIDS in the world, an extremity which can be partly attributed to the social engineering and neglect that was entrenched during colonial and Apartheid rule of the country. However, it began only to be identified as a political priority after the transition to democracy in 1994. My research suggests that the epidemic has consequently been, in a number of ways, narratively employed to interpret or signify truths about the state of the new nation. The remainder of the chapters examines the intersections between HIV/AIDS, its treatment and South African narratives. Exploring this terrain through various themes such as silence and stigma; Thabo Mbeki and ‘AIDS denialism’; the post-apartheid state; alternative health knowledges and gender relations, I show that under conditions of epistemic injustice, different strategies of reading and knowledge production may be required to illuminate aspects of social reality that are too often concealed by dominant narratives.

## **List of abbreviations and acronyms**

ANC	African National Congress (of South Africa)
AIDS	Acquired Immunodeficiency Syndrome
ARVs	Antiretroviral drugs
ART	Antiretroviral therapy
AU	African Union
CMC	Computer Mediated Communication
DA	Democratic Alliance
EFF	Economic Freedom Fighters
GEAR	Growth, Employment and Redistribution programme
HAART	Highly active antiretroviral therapy
HIV	Human Immunodeficiency Virus
HSRC	Human Sciences Research Council
IDU	Injection Drug Use
IEC	Independent Electoral Commission
MCC	[South Africa's] Medicines Control Council
MSF	<i>Médecins Sans Frontières</i> (Doctors without Borders)
MSM	Men seeking Sex with Men
MTCT	Mother-to-Child Transmission (of HIV)
NACOSA	Networking HIV/AIDS Community of South Africa
NAP	National AIDS Plan
NEC	National Executive Committee (of the ANC)
NEPAD	New Partnership for Africa's Development
NGO	Non-Governmental Organisation

NIH	National Institutes of Health
NP	[Afrikaners] National Party
PACHA	Presidential Advisory Council on HIV/AIDS
PEPFAR	The President [of the United States]’s Emergency Plan for AIDS Relief
PLWHA	Persons living with HIV/AIDS
PMTCT	Prevention of Mother-to-Child Transmission
PrEP	Pre-Exposure Prophylaxis medication
RDP	Reconstruction and Development Programme
SADC	Southern African Development Community
SAHO	South African History Online
SAMJ	South African Medical Journal
SANAC	South African National AIDS Council
START	Strategic Timing of Antiretroviral Therapy study
TAC	Treatment Action Campaign
TRC	The Truth and Reconciliation Commission
UCT	University of Cape Town
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children’s Fund
UNISA	University of South Africa
WHO	World Health Organisation
WiSER	Wits Institute of Social and Economic Research
Wits	University of the Witwatersrand, Johannesburg

## **List of Illustrations**

- Figure 1. Nelson Mandela with TAC founder Zackie Achmat in 2002, both wearing the distinctive TAC ‘HIV Positive’ t-shirts. (Photograph: AFP)
- Figure 2. Protestors on a TAC march in November 2001 hold posters reading “Hope, Information, Victory” and “Thabo Mbeki, Your Ideas Are Toxic” (Photograph: Getty Images)
- Figure 3. Cartoon depicting Jacob Zuma reading from the ‘ABC of HIV Prevention’, with the words of his AIDS message being washed away by the shower he stands beneath. (Cartoonist: Zapiro)
- Figure 4 & 5. ACT UP posters reading Silence = Death and Silence = Mort.
- Figure 6. Tacoma Action Collective protestors perform a ‘die-in’ at the Tacoma Art Museum in December 2015 (Photograph: PostDefiance Editorial Staff)



### **Note on terminology and language**

In this thesis, I use the terminology for racial categories as used in the South African census, which includes the identity term “Coloured”, which refers to persons of mixed-race descent derived from Apartheid classifications and does not carry the same implications as it does in the United Kingdom and United States.

It should also be noted that the scope of this thesis is limited to narratives written in English, rather than in any of the other ten official languages of South Africa (isiZulu, isiXhosa, isiSepedi, isiTswana, isiNdebele, Tsonga, Venda, Sotho, Northern Sotho or Afrikaans). Issues around multilingualism, and different groups’ navigation or failure to navigate other languages, are highly relevant to the epistemic injustice that hampers both knowledge production and public health communication in the country. Even as English is widely used and fluently spoken, the use of this exogenous language as a lingua franca means that the research findings will be inherently self-selecting.

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## CHAPTER ONE – INTRODUCTION

First, the African human experience constantly appears in the discourse of our times as an experience that can only be understood through a negative interpretation.

Achille Mbembe, *On the Postcolony* (2001)

...there is a link between imagining disease and imagining foreignness. It lies perhaps in the very concept of wrong, which is archaically identical with the non-us, the alien.

Susan Sontag, *AIDS and its Metaphors* (1988)<sup>1</sup>

Within the academy, the past few decades have brought a steep rise in interest in the relationship between language and public health. Building on poststructuralist accounts of subjection, humanities scholars have endeavoured to build a “framework in which the relationship between health, discourse, power and society can be examined”.<sup>2</sup> By more-or-less corresponding with this upsurge in these new disciplinary and theoretical directions, the disease HIV/AIDS has the ambiguous distinction of being the first pandemic to strike humanity in the wake of widespread attention to medicine and health issues within the realms of literature and cultural studies, social sciences, history and anthropology. We might contrast the outpouring of writing prompted by HIV/AIDS with the catastrophic ‘Spanish’ flu epidemic that struck a century ago, which resulted in the deaths of between fifty and a hundred million people worldwide (an estimated 3-5% of the global population at that time),

<sup>1</sup> Achille Mbembe, *On the Postcolony* (Berkeley: University of California Press, 2001), p. 1; Susan Sontag, *AIDS and its Metaphors* (London: Allen Lane The Penguin Press, 1988), p. 48.

<sup>2</sup> Doris Boutain, 1999, cited in *Language and HIV/AIDS*, ed. by Christina Higgins and Bonny Norton (Bristol: Multilingual Matters, 2009), pp. 3

yet has left relatively little trace on our communal awareness of that period.<sup>3</sup> Our cultural reckoning with HIV/AIDS, meanwhile, has been so intensive and over-determined that scholars argue it has been integrated into the ways we understand phenomena of the most widespread to the most intimate natures.

HIV/AIDS has been a truly global pandemic, in that no country in the world has been unaffected by the disease; it both occurs in, and is taken to exemplify, our present stage of accelerated globalisation.<sup>4</sup> Troubled from the earliest days of its diagnosis by hyperbolic and morally alarmist coverage, the epidemic has generated prolific amounts of cultural myth-making.<sup>5</sup> Moralistic and inflammatory accounts of the epidemic were notably spread through the media and political discourse, tending to energise any forms of social discrimination already latent in societies and communities. They were however also disseminated within the academy itself,<sup>6</sup> meaning that studies of HIV/AIDS are in themselves potential sources to

<sup>3</sup> The 1918 flu epidemic predated the WHO's setting of global health goals, and additionally was overshadowed by the First World War (despite figures that suggest it claimed more lives than both World Wars put together). In terms of discourse, wartime censorship also meant that the US and European countries (outside of neutral Spain, hence its popularly being known as 'Spanish' flu) were unable to report freely on outbreaks. It could be argued that the 1918 flu exercises itself over public consciousness through the reformation of many countries' health ministries and establishment of socialised healthcare programmes in the 1920s. The related medical phenomenon of Encephalitis Lethargica, which entered the wider imagination through Oliver Sacks' book *Awakenings* (1973), is also a sign that the Spanish flu is still 'with us'. Nevertheless, the enormous scale of and suffering caused by the disease has not been proportionately reflected in narratives of the period. With the centenary of its acme, a number of scholars have begun to re-examine the phenomenon. For example, see Laura Spinney, *Pale Rider: The Spanish Flu of 1918 and How it Changed the World* (London: Penguin, 2017) for a recent work which aims to restore the centrality of this pandemic to the history of the twentieth century.

<sup>4</sup> For example, Cindy Patton argues that our understanding of globalization, meaning the contemporary phase of increased social interdependency, was emphatically rerouted by the concurrent emergence of the threat of HIV/AIDS: "Global proximity no longer promised wondrous cultural explorations; rather, it seemed to facilitate the spread of exotic new diseases that were not only deadly to individual bodies, but also threatening to the body politic [and] to its humanitarian ideals" (Cindy Patton, *Globalizing AIDS* (Minneapolis: University of Minnesota Press, 2002), p. x.

<sup>5</sup> See Susan Sontag, *AIDS and its Metaphors* (London: Allen Lane The Penguin Press, 1988; Paula Treichler, *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS* (Durham: Duke University Press, 1999).

<sup>6</sup> See for example Helen Epstein, *The Invisible Cure: Africa, the West and the Fight Against AIDS in Africa* (New York: Farrar, Strauss and Giroux, 2007), p. 51-53; Jean Comaroff and John Comaroff, *Theory from the South: Or, how Euro-America is Evolving Towards Africa* (London: Routledge, 2012); David Dickinson, *A Different Kind of AIDS: folk and lay theories from a South African township*, Auckland Park, Johannesburg: Fanele 2014).

illuminate the development of the current sociological imagination: as the anthropologists Jean and John Comaroff put it, “[w]e may lack the nerve or imagination to theorise [AIDS] adequately, but it certainly has been theorising us for quite a while”.<sup>7</sup> Even as the story, memory and lived experience of the epidemic has changed drastically over the course of the past three decades, all of this suggests that understanding the symbolic genealogy of HIV/AIDS continues to provide important insight into the global society we inhabit and forge. Moreover, the lessons taught to us by the HIV/AIDS epidemic may help us to navigate future large-scale health crises that are predicted to strike in the near-future.<sup>8</sup>

As with all cases of globalisation, HIV/AIDS was, and is, experienced in myriad localised terms. Epidemiological patterns and drivers differ from country to country and region to region, as do the diverse moral, spiritual and sanitary anxieties activated by the epidemic.<sup>9</sup> This study draws on the heightened interest in narrative and discourse as relating to health, power and society that has emerged within the academy during recent decades, and brings these ideas together with insights from postcolonial scholarship to examine how HIV/AIDS has manifested as a social phenomenon in the post-Apartheid South African context. South Africa is currently the country with the highest burden of the disease in the world: at time of

<sup>7</sup> Jean Comaroff and John Comaroff, *Theory from the South* (2012), pp. 174.

<sup>8</sup> In David Dickinson’s study of alternative, non-scientific paradigms of HIV/AIDS in South Africa, he writes that “if the epidemic is finally being contained, then isn’t this jeremiad simply a distraction? [Won’t dissident discourses] not become irrelevant to all but social historians? Yet, the AIDS epidemic is not the first time that expert and popular conceptions have differed. Nor will it be the last. Engaging with this gap between expert and subject may raise uncomfortable questions, but we are better off knowing what people really think” (Dickinson 2014, p. xxvii). In addition, epidemiologists, global public health leaders and vaccine manufacturers agree that another pandemic outbreak is inevitable – and that we are underprepared for it (World Bank, ‘From Panic and Neglect to Investing in HIV Security: Financing Pandemic Preparedness at a National Level’ (2017), <<http://www.worldbank.org/en/topic/pandemics/publication/from-panic-neglect-to-investing-in-health-security-financing-pandemic-preparedness-at-a-national-level>> [Accessed 7<sup>th</sup> September 2018])

<sup>9</sup> Drivers of HIV are also not immutable and acclimate along other co-occurring vectors present in each society. For example, in China, the key driver of the original epidemic was infections via shared needles used during blood-selling, a practice affecting impoverished communities. In the United States, the current opioid epidemic has led to a spike in new HIV infections, after two decades of declining rates of infections attributed to injection drug use (IDU) (CDC 2017).

writing, an estimated 7.52 million people in the country are living with HIV, which represents a prevalence of 13.1%.<sup>10</sup> As the HIV/AIDS epidemic struck the world, South Africa was transitioning from the Apartheid state into a new racially integrated democracy, and the country's socio-historical circumstances would radically affect the way that the disease was experienced, interpreted and narrated.

Numerous scholars of the postcolonial condition have identified ways in which readings of Africa tend to be mediated by Eurocentric optics which have historically constructed the continent at the opposite end of a binary between itself and Other-ness.<sup>11</sup> The discourses that emerged with the aim of analysing and producing understanding about HIV/AIDS in (South) Africa were not exempt from these kinds of reading (perhaps especially unsurprising given how, as Ryan Conrad has written, “[d]oing the history of AIDS in any capacity [...] always seems to be condemned to high-stakes inaccuracies, partial truths and flattened complexities no matter how hard one tries otherwise”).<sup>12</sup> Habits of thinking of Africa and Europe as polarities in fact played their part in the production of the global AIDS discourse, so that patterns of AIDS incidence were initially identified as Pattern One (signifying predominantly cases found among MSM and injecting drug users in Europe and North America) and Pattern Two (signifying predominantly heterosexually active people in Africa), and quickly took on the labels ‘Western AIDS’ and ‘African AIDS’. The historian Cindy Patton has described how “obfuscatory ideas about risk behaviours [produced] an epidemiological mapping of the world that continues to profoundly affect how we understand AIDS as a *pandemic*”, with the

<sup>10</sup> Stats SA, ‘Mid-year population estimates’, <http://www.statssa.gov.za/publications/P0302/P03022018.pdf> [accessed 28th August 2018].

<sup>11</sup> See for example Njabulo Ndebele, *South African Literature and Culture: rediscovery of the ordinary* (Manchester: Manchester University Press, 1994); Achille Mbembe, *On the Postcolony* (2001); Ngũgĩ wa Thiong'o, *Secure the Base: Making Africa visible in the Globe* (Chicago: University of Chicago Press, 2016).

<sup>12</sup> Ryan Conrad, 'Revisiting AIDS and its Metaphors', *Drain*, 13.2, (2016), <<http://drainmag.com/revisiting-aids-and-its-metaphors/>> [accessed 28 August 2018].

scheme “quickly [taking] on a narrative life of its own, offering supranational policy makers and news reporters a veneer of scientific objectivity for what were essentially racist and class-disadvantaging representations of local epidemics”.<sup>13</sup>

This thesis aims to intervene in the discursive canon that has formed so far on HIV/AIDS in post-Apartheid South Africa. In particular, it finds complications that have hindered efforts to tackle HIV/AIDS to be revelatory of the ongoing legacy of colonial public health practices, that is perpetuated by epistemically unjust processes that centre the Global North in decision-making on behalf of developing nations. The philosopher Miranda Fricker defines epistemic injustice as “a distinctive class of wrongs, namely those in which someone is ingenuously downgraded and/or disadvantaged in respect of their status as an epistemic subject”.<sup>14</sup> The process of being Othered is redolent with this concept, because the Othered person is prevented from ‘telling her story’ and from expressing expertise about her own condition and experiences; instead, she is constructed as available for intellectual appropriation, explanation and taxonomy. Fricker’s concept should be understood to mean more than recognising epistemological differences, whereby a person may be understood to perceive social reality using different tools. Rather, it provides an analytic grasp on the consequences for knowledge production and the legitimacy of socio-epistemic institutions when certain forms of knowledge are institutionally devalued. Threaded throughout the thesis are discussions of how those in the business of narrative production, relating to HIV/AIDS in post-apartheid South Africa, recognise and react to their epistemic disadvantage, and the narrative strategies they may pursue in order to redress this form of injustice.

<sup>13</sup> Cindy Patton, *Globalizing AIDS* (2002), pp. xi-xii.

<sup>14</sup> Miranda Fricker, *Epistemic Injustice: Power and the Ethics of Knowing* (Oxford: Oxford University Press, 2007), p 53.

The organising question of the thesis is how HIV/AIDS as a social phenomenon has been understood and communicated through various contemporary South African narratives. These narratives include novels, memoirs, biographies and non-fiction texts, which are connected by an interest in discursively exploring the new nation through the lens of the epidemic. While it is interested in literary concerns around representation and genre, it also aims to uncover how other kinds of narratives and discourses have circumscribed those of post-Apartheid South Africa and intervened in its social reality. This takes place at the political level, in what I will show is the circumscribed freedom possessed by the postcolony to determine its present, as well as at an epistemic level, referring to the ways that knowledge and cultural production are subjected to monitoring, regulation and erasure. In South Africa and in postcolonial / neocolonised terrains more generally, the interplay between health, discourse, power, and society has been complicated further by the impact of the colonial encounter on each of those categories of analysis.<sup>15</sup> Writing just four years after the end of apartheid, Sarah Nuttall wrote, in relation to “[p]ublic acts of remembering – individual memory in action”, that “it will also be important to see how this messy activity of memory, this intricate crossing of the individual and social, has been subject in South Africa, to particular pressures and distortions”.<sup>16</sup>

\*

<sup>15</sup> It would not be sufficient to merely add “race” to this list of categories because while our systems of health, power and society are dependent on discursive construction, those discourses themselves have been reliant on categories such as race, gender and sexuality to become coherent.

<sup>16</sup> Sarah Nuttall, 'Telling 'free' stories? Memory and democracy in South African autobiography since 1994', in *Negotiating the past: The making of memory in South Africa*, ed. by Sarah Nuttall and Carli Coetzee (Cape Town: Oxford University Press, 1998), p. 76.



Even now, there is not a single established narrative of HIV/AIDS. In the most widely visible or recognised versions, the HIV/AIDS story seems to ‘begin’ when it is first diagnosed as a distinct medical condition in the early 1980s in cosmopolitan North American cities of Los Angeles, New York and San Francisco and then officially isolated by researchers at the Pasteur Institute in France in 1983. Another household narrative is that of ‘Patient Zero’: a flight attendant named Gaëtan Dugas who was alleged to be the origin of the virus’s intercontinental spread in Randy Shilts’s bestselling book *And the Band Played On: Politics, People and the AIDS epidemic* (1987).<sup>17</sup> The first recorded death from AIDS in the United States is however now known to have occurred as early as 1969, when an African-American sixteen-year-old boy named Robert Rayford passed away in Missouri from unexplained symptoms. His doctors were sufficiently mystified by the cause of death to save tissue from his body, and an autopsy carried out in 1987 confirmed surmises that he had contracted HIV, contradicting the initial picture of how and when the virus had first been transmitted to the United States.<sup>18</sup> Rayford remains a relatively unknown figure, however, and Ted Kerr argues that because “an essentialised AIDS identity had already been cemented [as] solely queer” in the general imagination, the erasure of his story means that “the story of other Black and brown people who lived with HIV/AIDS before the AIDS crisis might also be lost or forgotten. How do we begin to see those who died of AIDS *before* AIDS?”<sup>19</sup>

<sup>17</sup> Two decades later, in an “interview with scholar Phil Tiemeyer, Shilts’s editor Michael Denny admitted that Patient Zero was a construction” (Theodore Kerr 2016). See also Richard A. McKay, *Patient Zero and the Making of the North American AIDS Epidemic* (Chicago: University of Chicago Press, 2017), for an in-depth examination of the epidemiological context in which the idea of Patient Zero was coined.

<sup>18</sup> The Patient Zero narrative both centres the Global North as a point of origin for meaning-making, while simultaneously locating the epidemic beyond the borders (Dugas’ profession as a flight attendant characterised him as an itinerant, and his alleged promiscuity in countries including Haiti contributed to his construction as an Outsider-insider). The symbolic displacement of HIV/AIDS to Africa is another way in which Western narratives attempt to distance the epidemic.

<sup>19</sup> Theodore Kerr, ‘AIDS 1969: HIV, History and Race, Drain, 13.2, (2016), < <http://drainmag.com/aids-1969-hiv-history-and-race/> > [accessed 28 August 2018].

This question has pertinence beyond the North American context. HIV/AIDS scientists now concur that the virus spread silently across the globe for decades before it was first formally diagnosed in San Francisco in 1981. Epidemiological modelling suggests that the first instance of mutation from Simian Immunodeficiency Virus (SIV) to HIV in humans took place in Kinshasa, Democratic Republic of Congo as early as the 1920s or 1930s – meaning that the first cases could have been contemporaneous with the Spanish Flu.<sup>20</sup> The first time HIV infection reached epidemic proportions through heterosexual transmission is also believed to have taken place in Kinshasa in the 1970s. In historian John Iliffe’s view, “the question posed most provocatively by President Mbeki of South Africa: Why has Africa had a uniquely terrible HIV/AIDS epidemic?”, is answered by this fact that the disease was established among populations in Africa decades before it was discovered and recorded.<sup>21</sup> The sub-Saharan African region has experienced an exceptionally severe burden of the disease, although ironically, the virus appeared relatively late there, with East Africa the initial focus of global concern:

In the late 1980s, scientists, in South Africa as elsewhere in the world, were wondering why this region was spared the disease which had so severely affected the rest of the continent ... and were proposing hypotheses about the lower virulence of the virus or the different exposure to risk. One decade later, the country was considered as the most affected on the planet.<sup>22</sup>

Unlike most other viruses, such as influenza (1 – 2 days), smallpox (12 – 14 days), or Ebola (2 – 21 days), HIV-1 has an uncommonly long incubation period: in the average adult, there

<sup>20</sup> Nuno R. Faria et al, ‘The early spread and epidemic ignition of HIV-1 in human populations’, *Science*, 346(6205), 56-61. doi: [10.1126/science.1256739](https://doi.org/10.1126/science.1256739)

<sup>21</sup> John Iliffe, *The African AIDS Epidemic: A History* (Oxford: James Currey Press, 2006), pp. 1

<sup>22</sup> Didier Fassin, *When Bodies Remember: Experiences and Politics of AIDS in South Africa* (Berkeley: University of California Press, 2007), p. 309

may be a period of ten years before the immune system is so weakened that AIDS supervenes. This was in part why the epidemic took time to manifest visibly as a pervasive clinical issue in Africa, particularly because deaths from AIDS can be easily mistaken for or attributed to the diseases to which people with weakened immune systems become susceptible. Delays to confronting HIV/AIDS were also exacerbated by the clinical misidentification of the disease in some areas, for example in Uganda, where the epidemic was recorded in *The Lancet* in 1985 as a ‘new’ disorder called Slim Disease.<sup>23</sup> Global coordination of public health efforts followed in being slow to materialise, so that “the first epidemic did not produce the first response”.<sup>24</sup> The first priority of Global North countries, in an internationally-oriented sense, was to protect their borders from the disease rather than to assist afflicted countries, a strategy that has also had lasting consequences for migration policies and rhetoric regarding the policing of borders.<sup>25</sup> Helen Epstein notes that “tactless headlines like ‘Doomsday Reports Shock Whitehall: African AIDS ‘Deadly Threat to Britain’ angered African leaders and intellectuals across the continent”, and this compounded

<sup>23</sup> Serwadda et al., ‘Slim disease: a new disease in Uganda and its association with HTLV-III infection.’, *The Lancet*, 19.2, (1985), pp. 849-52.

<sup>24</sup> Iliffe, *The African AIDS Epidemic: A History*, p. 65.

<sup>25</sup> Brown, Cueto and Fee (2006) note that the preference for the terminology of ‘global health’, implying the consideration of the health needs of people in the whole planet as an agenda above the concerns of particular nations, developed only recently, around the turn of the millennium (Theodore M. Brown, Marcos Cueto, and Elizabeth Fee, ‘The World Health Organization and the Transition from ‘International’ to ‘Global’ Health in *Medicine at the Border: The History, Culture and Politics of Global Health*, ed. Alison Bashford (London: Palgrave, 2006). This expansive trend has been countered by an increased suspicion of outsiders, as Renisa Mawani observes: “[w]hile crime and terrorism have (re)emerged as strategies of border control [...] public health has also resurfaced as an issue of national security and once again figures prominently in reinscribing national borders by determining who belongs inside and outside the nation” (Renisa Mawani, ‘Screening out Diseased Bodies: Immigration, Mandatory HIV Testing and the Making of a Healthy Canada’, in *Medicine at the Border: Disease, Globalization, and Security, 1850 to the Present*, ed. by Alison Bashford (London: Palgrave, 2006), p. 137-138). AIDS continues to be invoked in xenophobic rhetoric that promotes restricting immigration; in the leaders’ debate televised in the run-up to the UK’s 2015 General Elections, for example, the UKIP leader Nigel Farage falsely claimed that 60% of the 70,000 people treated for HIV in the UK had come to the country from abroad in order to benefit from the NHS (Kmietowicz 2015).

lacklustre responses from some African governments by provoking a tendency to downplay the significance of the epidemic within their borders.<sup>26</sup>

As antiretroviral medications came into widespread use in Global North countries from the late 1990s, HIV/AIDS began to become reconfigured from a fatal and panic-inducing diagnosis to a manageable, if chronic, condition. The new drugs, first presented at the ninth International AIDS Conference in Vancouver in 1996, were so effective that AIDS death rates in developed countries dropped by an estimated 88% over the next four years.<sup>27</sup> In the continued absence of a cure, prevention and treatment became the main focus in the global public health narrative. However, this new assurance omitted the fact that in poorer countries, where people without access to the exorbitantly expensive medications continued to die from AIDS at catastrophic rates. This shift in the epicentre of the disease would contribute to the controversy in South Africa in the early 2000s in which the ANC government, under Presidents Nelson Mandela and Thabo Mbeki, refused to provide antiretroviral treatment through the public health system on the grounds that it was unaffordable and potentially harmful. At the thirteenth International AIDS Conference, held in Durban in July 2000, President Mbeki shocked the assembled delegates and reporters by identifying “extreme poverty” as the bigger cause of death and disease on the continent, and querying whether “safe sex, condoms and anti-retroviral drugs [were] a sufficient response to the health catastrophe”.<sup>28</sup> As will be examined in further detail during this thesis, the struggle over anti-

<sup>26</sup> Helen Epstein, *The Invisible Cure: Africa, the West and the Fight Against AIDS in Africa* (New York: Farrar, Strauss and Giroux, 2007), p. 50.

<sup>27</sup> JAMA and Archives Journals, ‘Since Introduction Of Highly Active Antiretroviral Therapy, HIV Death Rate Has Decreased’ ScienceDaily (3 July 2008) <[www.sciencedaily.com/releases/2008/07/080701165100.htm](http://www.sciencedaily.com/releases/2008/07/080701165100.htm)>. [Accessed 7<sup>th</sup> September 2018]

<sup>28</sup> Thabo Mbeki, ‘Speech by Thabo Mbeki at the Thirteenth International AIDS Conference, July 9, 2000’, in *Africa and the West: a Documentary History: Volume 2: From Colonialism to Independence* ed. by William H. Worger, Nancy L. Clark and Edward A. Alpers (Oxford: Oxford University Press), p. 234.

retroviral treatment (ART) would indelibly contour the narrative of HIV/AIDS in the country, as well as that of South Africa itself.

I am writing at what is potentially a historic turning point in the story of the epidemic worldwide. In November 2015, the Joint United Nations Programme on HIV/AIDS published a report that declared that: “[t]he world has halted and reversed the spread of HIV. The epidemic has been forced into decline”.<sup>29</sup> In that year, around 17 million people worldwide had access to the antiretroviral drugs (ARVs), which halt the virus’ progression to AIDS - a sharp rise from 7.5 million five years earlier. As of 2016, more than half of all people living with HIV now have access to ART.<sup>30</sup> One of the UN’s Sustainable Development Goals (2015 – 2030), whose tenure succeeds that of the Millennium Development Goals (2000 – 2015), is for the world to see the end of AIDS as a global public health threat as early as 2030. Recent other leaps in the field have included: new protocol based on findings exhibiting better outcomes for patients introduced to regimens of ARVs immediately after infection, rather than, as previously, only when their immune system declined to a certain level;<sup>31</sup> strengthened hopes that the discovery of an HIV vaccine is in sight;<sup>32</sup> and studies confirming the effectiveness of pre-exposure prophylaxis (PrEP) medication – a combination anti-retroviral pill which, taken after sexual contact, drastically reduces the likelihood of sexual

<sup>29</sup> UNAIDS, ‘AIDS by the numbers: 2015’

<[http://www.unaids.org/sites/default/files/media\\_asset/AIDS\\_by\\_the\\_numbers\\_2015\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/AIDS_by_the_numbers_2015_en.pdf)> [accessed 28 August 2018].

<sup>30</sup> UNAIDS, ‘Ending AIDS: Progress towards the 90-90-90 targets’ (2017).

<sup>31</sup> Adrian O’Dowd, ‘Experts plan to recommend immediate antiretroviral therapy for people with HIV’, *BMJ* 250 (2015), doi: <https://doi.org/10.1136/bmj.h2963>

<sup>32</sup> Most recently, BBC, ‘HIV vaccine shows promise in human trial’ (7 July 2018), <<https://www.bbc.com/news/health-44738642>> [Accessed 7<sup>th</sup> September 2018]

transmission.<sup>33</sup> Together, these developments augur that the exponentially improved but inevitably imperfect tactics of treatment, education and prevention will no longer be the only tools in the fight against the spread of the virus.

South Africa has to some extent emerged as a leading player in these global efforts.<sup>34</sup> Faced with the greatest burden of the disease, its ART programme is the largest in the world and almost completely self-funded. This is no mean feat: with around 4.4 million people receiving ARVs,<sup>35</sup> the middle-income economy country consumes as many ARVs as North America, Asia and the Pacific, and Western and Central Europe combined. Deaths from AIDS-related causes have fallen from 276,921 in 2007, to 115,167 in 2018.<sup>36</sup> At the end of 2015, South Africa also became the second country after the United States to make PrEP available within the public health system, placing it at the forefront of HIV care provision.<sup>37</sup> The World Health Organisation also recognised South Africa as the first country to translate their recommendation of providing PrEP to sex workers into national policy, through the launch of the National Sex Worker HIV Plan in March 2016. In the same year, the International AIDS Conference returned to Durban, making the city the first in the world to have hosted the conference more than once, a distinction that spoke to the country's critical

<sup>33</sup> Pamela M. Murnane et al, 'Efficacy of pre-exposure prophylaxis for HIV-1 prevention among high risk heterosexuals: subgroup analyses from the Partners PrEP Study', *AIDS*, 27(13), (2013) doi: 10.1097/QAD.0b013e3283629037; RM Grant et al, 'Uptake of pre-exposure prophylaxis, sexual practices, and HIV incidence in men and transgender women who have sex with women: a cohort study', *Lancet Infectious Diseases* 14(9), (2014) doi: 10.1016/S1473-3099(14)70847-3.

<sup>34</sup> UNAIDS, 'South Africa at the forefront of the global AIDS response' (2016), <[http://www.unaids.org/en/resources/presscentre/featurestories/2016/april/20160415\\_SouthAfrica](http://www.unaids.org/en/resources/presscentre/featurestories/2016/april/20160415_SouthAfrica)> [Accessed 7th September 2018]

<sup>35</sup> Human Sciences Research Council, 'HIV Impact Assessment Summary 2018'.

<sup>36</sup> Stats SA, 'Mid-year population estimates', <http://www.statssa.gov.za/publications/P0302/P03022018.pdf> [accessed 28th August 2018]

<sup>37</sup> Andrew Tucker et al, 'SA registers a two-in-one pill that can prevent HIV infection' <<https://bhakisisa.org/article/2015-12-09-sa-registers-a-two-in-one-pill-that-can-prevent-hiv-infection>> [accessed 28 August 2018].

place in global AIDS history. The conference was an occasion for reflection on the ground gained since the community had last gathered in Durban in July 2000: as the President of the International AIDS Society Chris Beyrer remarked in his opening speech, “How the world has changed in the past 16 years!”<sup>38</sup>

Nevertheless, despite invigorating rhetoric about the foreseeable ‘end’ of HIV/AIDS, the disease continues to present one of the world’s greatest contemporary healthcare and humanitarian challenges. There are currently over seven million people estimated to be living with HIV in South Africa and a total of between 31.1 million and 43.9 million worldwide.<sup>39</sup> In addition, there are signs that the epidemic is on the uptick in countries where previously it had been considered tamed. Eastern and Central Europe is also emerging as a new region of concern with a surge of 60% more new infections since 2010.<sup>40</sup> A new wave of AIDS activism is emerging in response to re-mounting incidences, plateauing of global financial commitments, and severe political threats to existing programmes. It would therefore be inappropriate here, particularly as a layman and humanities scholar, to present excessively optimistic conclusions based on recent advances.<sup>41</sup> However, it seems equally disingenuous

<sup>38</sup> Chris Beyrer (Personal notes 2016). New optimism about a cure was also reflected in the programme of the 2016 IAIDS conference, with increased amounts of funding, scientific research and attention driving discussions around the topic.

<sup>39</sup> HSRC, The Fifth South African National HIV Prevalence, Incidence, Behaviour and Communication Survey, (2017) <[http://www.hsrc.ac.za/uploads/pageContent/9234/SABSSMV\\_Impact\\_Assessment\\_Summary\\_ZA\\_AIDS\\_clear\\_ed\\_PDFA4.pdf](http://www.hsrc.ac.za/uploads/pageContent/9234/SABSSMV_Impact_Assessment_Summary_ZA_AIDS_clear_ed_PDFA4.pdf)> [Accessed 7th September 2018]; UNAIDS, 'Global HIV and AIDS statistics - 2018 fact sheet', (2018) <<http://www.unaids.org/en/resources/fact-sheet>> [Accessed 7th September 2018]

<sup>40</sup> UNAIDS, ‘Ending AIDS: Progress towards the 90-90-90 targets’ (2017).

<sup>41</sup> Not least because, as with other structural disadvantages, the ‘end’ of AIDS will be staggered, and is likely to represent a displacement onto the most vulnerable. The election of Donald Trump to the Presidency of the United States – the country which is the single largest donor to global health efforts - is also likely to represent a step back in global AIDS programmes. Further to Trump’s reinstating of the ‘global gag rule’ in January 2017, six of the members of the Presidential Advisory Council on HIV/AIDS (PACHA) resigned in September 2017 stating that the Trump Administration “simply does not care” about HIV/AIDS and furthermore, pushes legislation that will “halt or reverse important gains made in the fight against this disease” (Scott A. Schoettes, ‘Trump doesn’t care about HIV. We’re outta here’ (2017), <<https://www.newsweek.com/trump-doesnt-care-about-hiv-were-outta-here-626285>> [Accessed 7th September 2018].

not to acknowledge how carrying out research at this particular historical moment inherently impacts the perspective and tone of my thesis. I offer as a contrast Stuart Hall writing bleakly on the subject of the AIDS epidemic in the early 1990s:

Against the urgency of people dying in the streets, what in God's name is the point of cultural studies? [...] if there is no response to the question of what you say to somebody who wants to know if they should take a drug and if that means they'll die two days later or a few months earlier?<sup>42</sup>

Hall's question highlights the disjoint between the scholar and the 'people in the streets' and above all between the timeframes of academic labour and everyday suffering. In the midst of such a devastating crisis, writing seemed to him a redundant and rarefied pursuit, perhaps even insultingly so ("what in God's name is the point...?") Yet this lag between experience in the present and narrative, history and memory implies possibilities which this thesis wishes to explore further. Hall went on in his essay to endorse the 'deadly seriousness' of doing theory, observing that one effect of the epidemic was to focus attention on the "question of who gets represented and who does not", a question which is of course closely linked to who suffers and who does not.<sup>43</sup> Public narratives that have emerged around the HIV/AIDS epidemic in South Africa are profoundly concerned with this question. In the aftermath of the Apartheid regime, in which surface markers of identity were essentialised and racialised in ways that warped the social fabric, notions of representation and visibility have perhaps naturally become pivotal to the new democracy's projects of social justice and reparation.

<sup>42</sup> Stuart Hall, 'Cultural Studies and its Theoretical Legacies', in *The Cultural Studies Reader*, ed. by Simon During, 2nd edn. (New York: Routledge, 1998), pp. 105.

<sup>43</sup> Stuart Hall, 'Cultural Studies and its Theoretical Legacies' (1998), pp. 106.



As an anticipatory point on some of the epistemic limitations to this thesis, I will admit that when my application to carry out this research project was accepted four years ago, I envisaged being able to isolate HIV/AIDS as an issue of health sociology, and to ground both the research questions and the findings in a self-enclosed national context. I planned to - wherever possible - draw on sources ‘from’ the place and to deprioritise texts that I saw as falling under the Eurocentric, ethnographic gaze.<sup>44</sup> However, it soon became clear that our histories are too intertwined to truthfully write about either place in isolation, probably in all cases, but certainly in the case of the HIV/AIDS phenomenon. I position my thesis in line with the forecast made by Jean and John Comaroff that ‘Euro-America is evolving towards Africa’. Their argument is that contrary to the notion - common from the Enlightenment through to contemporary development discourse - that Western modernity is the parameter of progress, it is now in fact the Global South “that affords privileged insight into the workings of the world at large”.<sup>45</sup> In the epilogue, I link the arguments discussed in the thesis back to wider critical debates around racial politics and how while my study focuses on events and texts within the country’s borders, it must be seen to remain part of a larger discursive network and endeavour.

## **AIDS as Metaphor, Africa as Metaphor**

In Susan Sontag’s compelling works *Illness as Metaphor* (1978) and *AIDS as Metaphor* (1989), she criticised the destructive effects of the careless metaphorisation of illness. Having been herself diagnosed with cancer, she was “enraged [to see] how much the very reputation

<sup>44</sup> Many of the issues that I identify and critique during this study can naturally be applied to my own work, and I recognise that I do and will benefit from the project of writing a doctoral thesis in ways which fall short of the ethical standards that I may hold other authors to.

<sup>45</sup> Jean Comaroff and John Comaroff, *Theory From the South* (2012), p. 1.

of this illness added to the suffering of those who have it”.<sup>46</sup> The later book builds on the insights of the first to describe how AIDS had surpassed cancer as the disease “most fraught with meaning” in [Western] society.<sup>47</sup> Like cancer, and tuberculosis before it, the virus quickly accrued a plethora of tenacious and unflattering associations. The portrayals which she argued contained particular metaphorical resonance were those that described AIDS as an invasion, pollution and/or subversion. Although these hyperbolic comparisons were, much of the time, deployed with the aim of increasing the urgency and resolve with which the epidemic was addressed, these metaphors had the effect of exposing PLWHA to greater risk of harassment, exclusion and persecution by invoking social fears that would be directed at the virus’s carriers. In Sontag’s experience and theorisation, “the move from the demonization of the illness to the attribution of fault to the patient is an inevitable one, no matter if patients are thought of as victims”.<sup>48</sup>

Stigmas attached to PLWHA have indeed been among the key barriers to treating HIV/AIDS, with even doctors and health professionals struggling to conceal their fears and prejudices in the initial outbreak period.<sup>49</sup> The World Health Organisation (WHO) cites fear of discrimination as the main obstacle to people testing for the virus, adhering to medical advice

<sup>46</sup> Susan Sontag, *AIDS and Its Metaphors* (London: Allen Lane The Penguin Press, 1988), p.12

<sup>47</sup> Ibid, p. 93.

<sup>48</sup> Susan Sontag, *AIDS and Its Metaphors*, p. 99.

<sup>49</sup> Philip Strong for example records that “panic and irrationality can extend even to those who are nominally best informed about the disease. Experienced doctors could still turn hot and cold when they saw their first AIDS patient or be unable to extend the normal social courtesies to AIDS campaigners. Experienced natural scientists could find themselves unable to treat HIV like any other virus” (Philip Strong, ‘Epidemic Psychology: a Model, Sociology of Health and Illness, 12(3) (1990), p. 253). In a lecture titled ‘ART: Do or Die’ delivered at the Wits School of Public Health on 29th November 2016, Professor Francois Venter reminded the audience that ‘denialism’ flourished within research and clinical institutions when HIV/AIDS was first identified in South Africa (Personal notes, 2016). PLWHA continue to report the need for sensitivity training among healthcare practitioners in order to prevent alienating and stigmatising treatment, particularly where their health needs intersect with other marginalised identities.

or publicly disclosing their positive status.<sup>50</sup> Producing empirical evidence based on verifiable scientific principles consequently became necessary ballast in the midst of what initially seemed to be an uncontrollable virus, whose rampancy was only paralleled by a seemingly uncontrollable sensationalism.<sup>51</sup> Seeking to counter socially-produced fictions that would, in Erving Goffman's (1963) terms, 'spoil' the identity of PLWHA with fact, as well as to prevent inaccurate theories and speculations about the drivers of HIV/AIDS from taking root, the official production of knowledge about the HIV/AIDS epidemic has been chiefly structured by the biomedical perspective. Jean Comaroff has written that "AIDS activists often fetishize the language of science in their eagerness to limit the semantic resonance of discourse about the disease".<sup>52</sup>

To summarise as simply as possible, scientific research that has identified how a virus known as the human immunodeficiency virus (HIV) can be transmitted from person to person through bodily fluids including blood, semen, breast milk and vaginal, cervical and rectal secretions. As its name suggests, the virus depletes the immune system of the affected person, by attacking white blood cells called CD4 cells whose function is to fight infection. A normal range for CD4 cells in a person's body is 500 – 1500 per cubic millimetre of blood, but after a person has contracted HIV their CD4 count starts to drop. Once the CD4 count falls below 200, the person is often said to have developed 'full-blown' AIDS, (a semi-colloquial phrase that Sontag described as "primitively metaphorical")<sup>53</sup>, meaning that the immune system has

<sup>50</sup> UNAIDS, Reduction of HIV-related stigma and discrimination  
<<http://www.unaids.org/en/resources/documents/2014/ReductionofHIV-relatedstigmaanddiscrimination>>  
[accessed 28 August 2018].

<sup>51</sup> Paula Treichler has famously described AIDS as having unleashed an "epidemic of signification" (Paula Treichler, *How to Have Theory in an Epidemic* (1999), p. 1.

<sup>52</sup> Jean Comaroff and John Comaroff, *Theory From the South* (2012), p. 184.

<sup>53</sup> Susan Sontag, *AIDS and Its Metaphors* (1988), p. 28.

become so compromised that even infections such as the common cold can have fatal consequences. Treatment and prevention methods based on these empirical findings are the only kind to have been proven efficacious in halting the progress of HIV and prolonging the health and lives of PLWHA. Since their approval in 1995, antiretroviral drugs have been used to suppress the virus within a person allowing their body to rebuild and maintain a healthy CD4 count.<sup>54</sup> Transmission of the virus can also be prevented through refraining from unprotected sexual intercourse, breastfeeding and sharing of intravenous needles, and since 2015, the consistent use of PrEP.

Public health communication discourses draw forcefully on these facts, for the reasons described above. Yet one result of the tendency to ‘fetishize’ the biomedical has been an essentialisation of people affected by HIV/AIDS, suppressing the diversity of their concerns and lived experiences and producing one-dimensional identity types such as the ‘patient’ or the ‘risk group’ – “that neutral-sounding, bureaucratic category which also revives the archaic idea of a tainted community that illness has judged”.<sup>55</sup> The accentuation of impersonal, clinical language, which is assumed to be morally and culturally neutral, ironically erased much of the lived reality and sense of identity key to PLWHA’s experiences and illness journey. In order for the biomedical discourse to dominate and appear infallible, it

<sup>54</sup> Until recently, a person would only be started on an ARV treatment regimen once their CD4 count had dropped below 350. At the 2015 IAS Conference in Vancouver, results from the international START (Strategic Timing of Antiretroviral Therapy) study, which had included more than 4600 people from 35 countries, showed that starting ART early significantly reduced the rate of serious AIDS-related illnesses developing. About 98% of people who started treatment had an undetectable viral load at the end of their first year of treatment. Subsequently, the official guidelines were changed to recommend that a person should begin ART as soon as possible after being diagnosed HIV positive. See new World Health Organisation recommendations as of September 2015 (WHO, ‘Guideline on when to start antiretroviral therapy and on pre-exposure prophylaxis for HIV (2015),

<[http://apps.who.int/iris/bitstream/handle/10665/186275/9789241509565\\_eng.pdf;jsessionid=FADADA5BD77C180272EA518BA4897166?sequence=1](http://apps.who.int/iris/bitstream/handle/10665/186275/9789241509565_eng.pdf;jsessionid=FADADA5BD77C180272EA518BA4897166?sequence=1)> [Accessed 7<sup>th</sup> September 2018].

<sup>55</sup> Susan Sontag, *AIDS and Its Metaphors* (1988), p. 46.

was necessary to marginalise, along with the highly public moralistic and sensationalising discourses, a range of private, ‘minor’ discourses, including those of pleasure, romance and love;<sup>56</sup> gossip and humour;<sup>57</sup> indigenous health<sup>58</sup> and sadness and mourning, either for lost ones or for a different/former self. It also tends to suppress other incompatible discourses, such as religious conceptions of illness and suffering. Although these other discourses can sometimes find expression through less official channels, including literature, art, illness narratives, support groups or online fora, health researchers have found that the failure to provide space for PLWHA to express their experiences outside of a biomedical framing can deter adherence to medical advice and even act as a hindrance to recovery.

One of the aspirations of medical humanities, as a discipline, is to address this fissure between the pathological definition of disease and the subjective/social experience of illness, in the process creating a shared mode of inquiry that enriches not only the medical sciences but also the humanities. For example, the philosopher Havi Carel has argued that the tendency of philosophy to omit illness (by assuming a healthy adult subject, able in body and mind) has been unfortunate for the discipline’s development, because illness “challenges central philosophical concepts in moral and political philosophy such as fairness, autonomy and agency, but also in metaphysics, for example, by changing the experience of space and

<sup>56</sup> William J. Spurlin, ‘Postcolonial/Queer and the “New” South Africa: HIV/AIDS and Emerging Queer Transnational Politics’, *Etudes Anglaises* 61(3), (2008), pp. 360-370; R. H. Jones, ‘Learning about AIDS Online: Identity and Expertise on a Gay Internet Forum’, in Higgins, C. and Norton, B. (Eds.) (2010), *Language and HIV/AIDS* ed. by Christine Higgins and Bonnie Norton, (Bristol: Multilingual Matters, 2010); Mark Hunter, *Love in the Time of HIV/AIDS: Inequality, Gender and Rights in South Africa* (Bloomington: Indiana University Press, 2010).

<sup>57</sup> Susan Cotts Watkins and Ann Swidler, Ann. ‘Hearsay Ethnography: Conversational Journals as a Method for Studying Culture in Action’, *Poetics*, 37(2), (2009).

<sup>58</sup> Thokozani Xaba, ‘Marginalized medical practice: The marginalization and transformation of indigenous medicines in South Africa’, in *Another Knowledge is Possible: Beyond Northern Epistemologies*, ed. Boaventura de Sousa Santos, (London: Verso, 2007); David John Wilding Venn, ‘Rainbow Knowledges: Adolescence and Mental Health in Post-Apartheid South Africa’ (201), (unpublished master’s thesis).

time”.<sup>59</sup> Relatedly, the sociologist Arthur Frank’s study of illness narrative as a literary genre suggests that it emerged in order to reject biomedicine’s engulfing of patient experience, which converts pain and suffering into alienating, often unpronounceable terms, so that “the chart becomes the official story of the illness”.<sup>60</sup> He explains that the procedures of modern medicine can leave its patients feeling exploited and dehumanised, because they sense a threat to their individuality and the subjective particularity of their suffering, reducing their significance to the physician as merely a body on which they may carry out their vocation.

This reduction of the person to their corporeal presence represents an area of analytical common ground between medical humanities and other schools of criticism which challenge the Western Enlightenment construction of self, including postcolonial studies, queer studies, feminist studies and disability studies. As such, the social phenomenon presented by the HIV/AIDS epidemic in Africa thus represents the collision of two excessively metaphorised entities. In the opening to *AIDS and its Metaphors*, Sontag quotes Aristotle’s dictum that “metaphor consists of giving the thing a name that belongs to something else”,<sup>61</sup> and the political philosopher Achille Mbembe has objected that ‘Africa’ is the inaccurate appellation given to various negatively-coded states of being from which the West wishes to distinguish itself:

Africa, as an idea, a concept, has historically served, and continues to serve as a polemical argument for the West’s desperate desire to assert its difference from the rest of the world. In

<sup>59</sup> Havi Carel, *Phenomenology of Illness*, (Oxford: Oxford University Press, 2016), pp. 2. Carel has also developed Fricker’s concept of epistemic injustice in relation to power imbalances in the medical context. See Havi Carel and Ian James Kidd, ‘Epistemic Injustice in Medicine and Healthcare’, in *The Routledge Handbook of Epistemic Injustice*, ed. by Ian James Kidd, José Melina, Gaile Polhaus Jr (New York: Routledge, 2017). I go on to discuss Carel’s theorisation of illness as phenomenological further in Chapter Four, through a reading of Masande Ntshanga’s novel *The Reactive* (2014).

<sup>60</sup> Arthur Frank, *The Wounded Storyteller: Body, Illness and Ethics*, 2nd edn (London: University of Chicago Press, 2013), p. 5.

<sup>61</sup> Susan Sontag, *AIDS and Its Metaphors* (1988), p. 5.

several respects, Africa still constitutes one of the metaphors through which the West [...] develops a self-image [...] Africa, because it was and remains the fissure between what the West is, what it thinks it represents, and what it thinks it signifies, is not simply *part of* its imaginary significations, it is *one of* those significations.<sup>62</sup>

All too often, numerous African writers have protested, writing about Africa by non-Africans provides an occasion for the exercising of anxieties or fantasies, rather than a sincere attempt to portray its reality. These texts are therefore seen to be rife with misrepresentations and homogenisation, often relying on tropes drawn from early colonial expeditions and ethnographies. Josef Conrad's *The Heart of Darkness* (1899) has come to serve as an archetypal case of such problematic metaphorisation.<sup>63</sup> Its title refers both to the jungle in the tropical Congo – which is stereotypically depicted through a European narrator's perspective as an unruly, bewildering corner of the 'Dark Continent' – and to a more metaphysical state of blindness, possibly a primordial absence of morals in general. In his famous lecture on the novella, Chinua Achebe argued that Conrad presents Africa as “the antithesis of Europe and therefore of civilisation [which is] finally mocked by triumphant bestiality”.<sup>64</sup> The 'imaginary' elements of such depictions of Africa endow texts like Conrad's with the compelling, mythical duality that has been admired by critics and readers: however, it

<sup>62</sup> Achille Mbembe, *On the Postcolony* (2001), p. 2 (original emphasis).

<sup>63</sup> Tellingly, Mbembe opens *On the Postcolony* with an epigraph from Conrad's novella, a quotation also singled out at more length in Achebe's lecture: “No, they were not inhuman. Well, you know, that was the worst of it – this suspicion of their not being inhuman. It would come slowly to one. They howled and leaped, and spun, and made horrid faces; but what thrilled you was just the thought of their humanity – like yours – the thought of your remote kinship with this wild and passionate uproar” (Conrad 1899, cited in Achille Mbembe, *On the Postcolony* (2001), p. 1). The Kenyan writer Binyavanga Wainaina also appears to reference the novella's influence over Western discourse about the continent when he opens his famous satirical essay 'How to Write about Africa' with the instruction: “Always use the word 'Africa' or 'Darkness' or 'Safari' in your title” (Binyavanga Wainaina, 'How to Write about Africa', <<https://granta.com/how-to-write-about-africa/>> [Accessed 1st September 2018]) .

<sup>64</sup> Chinua Achebe *Hopes and Impediments: Selected Essays* (Cape Town: Random House South Africa, 1990), p. 2.

correspondingly profits artistically by denying the humanity and dignity of African people, in ways that Mbembe argues justify further “exclusionary and brutal practices towards others” that take place beyond the literary domain.<sup>65</sup> This causative relation between narrative and reality underscores Sontag’s observations that the metaphorical aggression of a ‘war’ or ‘fight’ against HIV/AIDS, and depiction of cancer as a ‘scourge’ or ‘plague’ riles up moral zeal which can incite harm towards the actual people affected by those diseases.

Due to the sheer force with which associations have accrued to them, both concepts (‘AIDS’ and ‘Africa’) remain in need of active rectification. The construction of both PLWHA and people from the postcolony as superlative sites of alterity overpowers their complex, diverse and textured reality, in ways that also obscure the real work that needs to be done towards supporting PLWHA around the world.<sup>66</sup> Mbembe has expounded on why discursive injustices done to the African continent - along with, but in his opinion, exceeding other formerly colonised regions - must be brought to the fore of our analysis. Until the accretion of harmful meta-text implicit in any discourse about African life is made explicit and challenged, his argument goes, the political, social and cultural reality cannot properly be made intelligible to outsiders. As he observes, that negation is:

<sup>65</sup> Achille Mbembe, *On the Postcolony* (2001), p. 2. Terence Rogers has argued that even more than Conrad, the popular fiction writer Henry Rider Haggard stands out as one of the most pivotal and influential figures in the creation of Africa “both as a territory within the imperial gaze and as an imaginative literary subject” which was projected through his writings “into the deeper reaches of common and educated understanding” (Terence Rogers, ‘Empires of the imagination: Rider Haggard, popular fiction and Africa’, in *Writing and Africa*, ed. by Mpalive-Hangson Msiska and Paul Hyland (London: Longman (1997)) p.103). Formerly deemed irrelevant within literary studies as a lowbrow genre author, recent rethinking of the relationship between imperialism and culture sees him as “one of the now acknowledged architects of colonial discourse” (p. 8), by helping to establish a cultural imagination that could justify and naturalise the political strategies.

<sup>66</sup> Emmanuel S. Nelson’s statement in the introduction to *AIDS: The Literary Response* in 1992 could be equally used to describe the ‘African’ body: “The advent of AIDS ... has literally made the body of the gay male an object of massive public curiosity and relentless cultural inquiry. His body is now widely perceived as a site of mysterious and fatal infections – a perception that has prompted its radical (re)othering and (re)medicalizing. The body has emerged as a supertext, a territory over which a bewildering number of competing medical, political and cultural fictions seek domination (Emmanuel S. Nelson, *AIDS: The Literary Response*, ed. By Emmanuel S. Nelson (New York: Maxwell Macmillan International, 1992) p. 3).”



the prior discourse against which any comment by an African about Africa is deployed. There is the language that every comment by an African about Africa must endlessly eradicate, validate, or ignore, often to his/her cost...<sup>67</sup>

An example of this prior discourse is what Giuliana Lund has termed the ‘medicolonial’ discourse, which has “associated [Africa] in the imperialist imagination with disease and death” in ways that were, at a practical level, deeply integral to the objectives of the colonial project.<sup>68</sup> Like missionaries, she writes, doctors viewed their work as part of a higher ‘civilising’ duty, in which ‘native’ people were seen as needing to change every facet of their social structures and practices to conform with European standards and customs. Therefore, the portrayal of Africa through metaphors of difference from and in opposition to the West’s conception of itself is not only offensive but *expedient*. Following the advent of germ theory in the latter part of the 19<sup>th</sup> century, the concepts of race and hygiene were gradually woven together to produce ideas about ‘social hygiene’ which justified forms of state control that favoured the settler/colonial groups. In this way, eventually “medicine became a means of controlling African bodies and minds and thus an instrument of imperialism”.<sup>69</sup>

Under principles that could be communicated in liberal, humanitarian terms, a plethora of invasive and unethical practices ensued under colonial rule, from forced sterilisation and medical experimentation on human subjects, to legal discrimination against, and ‘Apartheid’-style segregation of, the indigenous populations. At the same time, the high-quality medical care provided for settlers was systematically denied to those populations. This evinces how,

<sup>67</sup> Achille Mbembe, *On the Postcolony* (2001), p. 5.

<sup>68</sup> Giuliana Lund, ‘Healing the Nation: Medicolonial Discourse and the State of Emergency from Apartheid to Truth and Reconciliation’, *Cultural Critique*, 54, (2003), p. 90.

<sup>69</sup> Jean Comaroff (1993) in Giuliana Lund, ‘Healing the Nation’ (2003), p. 91.

in the postcolony – as well as for other disenfranchised communities (including women and LGBT people) - public health is a deeply epistemic issue. The socially and epistemically disadvantaged often have to struggle harder to access and to demonstrate their right to the basic services, safe and hygienic environments and equitable medical treatment that they have previously lacked, often coming up against discriminatory paradigms that deny the existence of these needs. In Fricker's terms, they are victims of testimonial injustice - the lack of credibility granted to a speaker as a knower or producer of knowledge, due to 'identity-prejudices' on the hearer's part.<sup>70</sup> This can take place at both a nationwide level, for example, through the delegitimising of indigenous branches of medicine, healing and science, as well as at individual case levels.<sup>71</sup> As such, the philosopher Andrea J. Pitts argues, "Western / Global Northern knowledge practices ... have never existed merely as forms of abstract argumentation... [A]s is a common theme among decolonial thought and praxis, knowledge production itself ... is a materially embedded set of social and historical phenomena".<sup>72</sup>

This converging metaphorisation of AIDS and of Africa – and doubling of otherness – can also be illustrated through Mbembe's concept of 'necropolitics'<sup>73</sup>. In his essay of the same name, he argues that Michel Foucault's definition of biopolitics (loosely, as the state's regulation of and interventions in the processes of life) is no longer the dominant explanatory

<sup>70</sup> Miranda Fricker, *Epistemic Injustice* (2007), p. 7.

<sup>71</sup> Studies in the US have demonstrated false beliefs held by medical workers that their black patients experience less pain than white patients, so that black patients are systematically under-assessed and mis-diagnosed when reporting identical symptoms to white counterparts. See CR Green et al, 'The unequal burden of pain: confronting racial and ethnic disparities in pain', *Pain Medicine* 4(3), (2003), 277-294; and Kelly M. Hoffman et al, 'Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites', *Proceedings of the National Academy of Sciences of the United States of America*, 113(16), (2016), 4296-430, doi: [10.1073/pnas.1516047113](https://doi.org/10.1073/pnas.1516047113).

<sup>72</sup> Andrea Pitts, 'Decolonial praxis and epistemic injustice', in *The Routledge Handbook of Epistemic Injustice*, ed. by Ian James Kidd, José Melina, Gaile Polhaus Jr (New York: Routledge, 2017), p. 150.

<sup>73</sup> Achille Mbembe, 'Necropolitics' (2003).

factor behind contemporary power relations, as these now instead govern over death, or ‘bare life’: life reduced to bare existence at the verge of death. This state of precarity is dealt or exported to certain populations in order to withhold it from others: in some cases, to practically eliminate it. The anthropologist Didier Fassin thus writes of the cultural anaesthesia issued by the objectification and marginalisation of populations for whom suffering is depicted as the natural order, so that “[c]ausing suffering and ignoring suffering are [...] the two faces of the same contemporary reality”:<sup>74</sup>

The fragmentary information we receive from an absolute elsewhere is enough for us<sup>75</sup> because it confirms our sense that cultures are incommunicable and, more radically, that social worlds are incommensurable. [...] In the tension described by Zygmunt Bauman between “the global elite” and “ever more localized rest”, there is no inequality more disturbing than that by which we decide what is interesting and what is not, who can still interest us and who no longer does.<sup>76</sup>

With regards to AIDS, this can be seen by how in countries such as the US the discourse currently centres around disease undetectability, a state of viral suppression possible only with access to lifelong treatment, while in other countries treatment remains out of reach for many.<sup>77</sup> Comaroff for example cites how “the UN special envoy for HIV/AIDS to the

<sup>74</sup> Didier Fassin, *When Bodies Remember* (2007), p. xii.

<sup>75</sup> The Western world, or those who consider themselves at the Centre. The use of the first-person plural in academic and anthropological writing is in itself revealing of who is included and excluded from the act of knowledge production, in this instance, whose inclusion is felt to be politically meaningful.

<sup>76</sup> Didier Fassin, *When Bodies Remember* (2007), p. xiii.

<sup>77</sup> In a 2008 edition of the Bulletin of Swiss Medicine, members of the Swiss Federal Commission for HIV/AIDS concluded that HIV-infected persons on anti-retroviral therapy (ARV) and with no other sexually transmitted infections cannot transmit HIV via sexual contact if their viral loads have been un-detectable for at least six months. Katrin Köppert and Todd Sekuler write that this development has transformed the metaphorical resonance of the disease, representing a “radical departure from the widespread imaginings of HIV-infection as a death sentence—in terms of social if not also biological death” (Katrin Köppert and Todd, ‘Sick Memory: On the Un-detectable in Archiving Aids’ (2016), <<http://drainmag.com/sick-memory-on-the-un-detectable-in-archiving-aids/>> [Accessed 7<sup>th</sup> September].

continent reported in 2005 that while the use of triple-dose therapy in the West had cut the numbers of children with HIV practically to zero, in Africa only 10% of pregnant, infected women have access to the means of preventing mother-to-child transmission”.<sup>78</sup> Today the figures may have improved, but the disparity in global health outcomes remains stark. The fact that the production of knowledge and global health policy tends to be centred in the metropolitan Global North meanwhile produces further health injustices, which affect the development of health policy and communications at a local level. The shift in rhetoric towards a post-AIDS era may risk exacerbating the epidemic for those in communities where programmes of treatment, care and support are still not guaranteed: it is therefore ever more crucial that “interventions must address and be situated within, rather than avoid, the interconnected systems of domination”.<sup>79</sup>

## **Decolonising African HIV/AIDS Discourses**

Achille Mbembe argues in *On the Postcolony* (2001) that the default way in which Africa is discursively mediated is precluded by preconceptions: “the African human experience constantly appears in our times as an experience that can only be understood through a *negative interpretation*”.<sup>80</sup> While Mbembe’s use of the word ‘negative’ most obviously refers to a tendency to interpret social reality in Africa as lacking or inferior compared to Western standards, which are assumed to be universal and universally desirable, I want also to play with the term’s different connotation in photography. In this meaning, the ‘negative’ of a

<sup>78</sup> Jean Comaroff and John Comaroff, *Theory from the South* (2012), p. 188.

<sup>79</sup> Ciann Larose Wilson et al, ‘Narratives of resistance: (Re) Telling the story of the HIV/AIDS movement’, *Health Tomorrow*, 4, (2016), p.24.

<sup>80</sup> Achille Mbembe, *On the Postcolony* (2001), p. 1.

camera film shows the object of the observer's gaze, but filtered in a way that distorts what you would ordinarily be able to observe. As viewers, we might get an idea of what is being represented, but we would need to fill in what is missing with our imagination, drawing on previous experiences, knowledge and/or images and reproductions of comparable scenes. The legacy of colonial thinking forms a similar filter through which although the outlines are represented, only certain aspects of reality can be accurately seen, while certain aspects are 'over-exposed' and others left out of the frame entirely.<sup>81</sup> Because the collective imagination is populated with stereotypes, misconceptions and simplifications – the metaphors and 'prior discourses' described in the previous section – the task of accurately recreating what is being represented from a 'negative' becomes more precarious. Meanwhile, conventions persist in framing what outsiders expect to see, so that in the same way that people visit tourist attractions in order to line up almost identical shots, narratives about Africa can seem to be looking through an old colonial viewfinder.<sup>82</sup>

Yet this is not merely a problem of researchers' positioning and situatedness: there is, at a collective or institutional level, an active investment in the production of certain silences (which also could be described as the process of silencing). Miranda Fricker has characterised the systematic denigration of certain persons' or groups' cognitive experiences or

<sup>81</sup> ("Taboo subjects", writes Binyavanga Wainaina wryly, include "ordinary domestic scenes, love between Africans (unless a death is involved), references to African writers or intellectuals, mention of school-going children who are not suffering from yaws or Ebola fever or female genital mutilation" (Binyavanga Wainaina, 'How to Write About Africa' (2006), no pagination).

<sup>82</sup> In March 2018, the magazine *National Geographic* published an edition aiming to examine its history and admitted reinforcing racial discrimination by portraying people of colour from outside the US through a reportorial gaze that saw them as "exotics, famously and frequently unclothed, happy hunters, noble savages – every type of cliché" (Susan Goldberg, 'For Decades, Our Coverage was Racist. To Rise Above Our Past, We Must Acknowledge It' (2018), <<https://www.nationalgeographic.com/magazine/2018/04/from-the-editor-race-racism-history/>> [Accessed 7<sup>th</sup> September 2018]. Writing for the edition, the historian of photography John Edwin Mason described how the power of the magazine's image-making perpetuated and entrenched those clichés: "They knew that there were problems with the way that their people were being represented. And yet the photography was often spectacularly good, it was really inviting, and [young people] said, I want to do that. I want to make pictures like that" (Ibid).

interpretations of the world as ‘epistemic injustice’, while the Portuguese sociologist Boaventura de Sousa Santos has advanced a similar concept of ‘epistemicide’ implying a rather more active intention against certain kinds of knowledge.<sup>83</sup> These concepts describe how power determines what forms of talk and knowing are permitted, and which forms are engulfed by a vacuum that seems even to cancel out the fact of their utterance. While epistemic injustice is in many ways characteristic of medicine’s expert-lay dichotomy, additional ideological weight has been deployed to enforce the borders around what constitutes legitimate knowledge against the non-Western context. In formerly colonised countries, epistemological norms continue to be dictated from the metropolitan capitals of the West, so that anything that fails to conform to these frameworks becomes irrelevant.

In recent years, the terms ‘decolonising’ and ‘decolonisation’ have gained traction both in the academy and in current praxis and activism, although they are used to encompass a diffuse range of meanings. What is perhaps shared is the assertion that while previously colonised countries can be said to have gained independence, the process of dismantling colonisation is unfinished and ongoing. The concept therefore sets itself against the idea of the ‘postcolonial’, which implies that a demarcation can be made between the two eras. Gayatri Chakravorty Spivak has accordingly coined the term ‘post-colonial neo-colonized world’ in order more accurately to apprehend a state *after* colonialism, in historical and constitutional terms, yet bearing both the legacy of those colonial practices and the reality of the current neo-colonial practices used to control and exploit former colonies.<sup>84</sup> Decolonising also deals

<sup>83</sup> Miranda Fricker, *Epistemic Injustice: Power and the Ethics of Knowing* (Oxford: Oxford University Press, 2007); Boaventura de Sousa Santos, *Another Knowledge is Possible: Beyond Northern Epistemologies*, (London: Verso, 2008) and *Epistemologies of the South: Justice Against Epistemicide*. (London: Routledge, 2014).

<sup>84</sup> Gayatri Chakravorty Spivak, 'The political economy of women as seen by a literary critic', in *Coming to Terms: feminism, theory, politics*, ed. by Elizabeth Weed, 2nd edn. (New York: Routledge, 1990).

with the internal, psychological work that is needed to redress the indoctrination methods that alienated people from their cultures, languages, history, economic systems and spiritual and moral beliefs, and constructed them solely as receptacles rather than autonomous producers of knowledge about the world: “[t]he colonizer was constructed as one who knows, while the colonized had to learn from the colonizer”.<sup>85</sup>

I consider the process of decolonising to include – to return to the illustrative image of the ‘negative’ – both putting the camera in the hands of the previously disempowered and restoring the ‘picture’ built up through colonialism to entirety. As such, it involves working with what exists (counter to critiques that calls to decolonise are destructive or nihilistic), but in a way that acknowledges and sincerely and actively aims to remedy inadequacies and fissures. Increased representation and diversity are not meaningful enough without these latter elements, which essentially entail changes at deeply structural and institutional levels. With reference to HIV/AIDS research, the prevailing negative space has important ramifications because new knowledge is produced with reference to, and building upon, what I argue is currently an incomplete and tendentious archive. Thus, scholarship produced in circumstances of epistemic inequality must simultaneously deconstruct and construct, by producing knowledge and promoting the unlearning of damaging claims currently accepted as knowledge. While the colonial encounter cannot be reversed, the lifting of imposed monocultural frameworks may allow epistemological ecosystems to recover.

As pertains to health and medicine, scholars have identified how assumptions that Western biomedical models comprise the totality of legitimate health knowledge has led to the

<sup>85</sup> Bagele Chilisa, 'Educational research within postcolonial Africa: a critique of HIV/AIDS research in Botswana', *International Journal of Qualitative Studies in Education*, (2005), p. 660.

submersion of alternative truths within the research literature. Maria Paula G. Meneses notes that:

In several studies produced in Africa, the act of situating the “other’s” knowledge becomes the key moment in the production of a relationship of inequality; from this standpoint, pre-modern forms of healthcare are characterized, *en bloc*, as traditional therapies, frequently of only local relevance (Meneses 2008, 352).<sup>86</sup>

Meneses thus insists that “[f]or knowledge to transform itself into solidarity [...] it is necessary to give that “other” culture the status of subject”.<sup>87</sup> That is to say that the invaluable expertise and capabilities of biomedical science can fulfil its potential to liberate people from sickness only by seeking to synergise with, rather than compete against and ultimately dominate, other forms of health expertise and wisdom. A notable difference is that while other systems of medicine tend to work alongside biomedicine, referring patients to these services where appropriate, biomedicine tends to see itself as the only solution.

This can be easily observed in the case of the HIV/AIDS field, where the imposition of interventions based on Western frameworks of knowledge and the diminishing of other systems of understanding and ontologies have produced less than desirable results; David Dickinson notes after two decades spent in the field in South Africa that “when it comes to behavioural change, it seems that this has come about largely despite our efforts and not because of them”.<sup>88</sup> Writing about the neighbouring country of Botswana, the scholar Bagele Chilisa observes that the country has “seen volumes of research on HIV/AIDS paralleled by

<sup>86</sup> Maria Paula Meneses, “‘When there are no problems, we are healthy, no bad luck, nothing’: towards an emancipatory understanding of health and medicine”, in *Another Knowledge is Possible: Beyond Northern Epistemologies*, ed. by Boaventura de Sousa Santos (Verso: London, 2008), pp.352.

<sup>87</sup> *Ibid*, 353.

<sup>88</sup> David Dickinson, *A Different Kind of AIDS* (2014), p. xxvi.



escalating HIV/AIDS prevalence and morality rates”, and accordingly argues that “the need for diversity in research epistemologies [is] an issue of life and death”.<sup>89</sup> Chilisa writes from a position of an intermediary: she is Botswanan by nationality and educated in the United States. In her 2005 paper ‘Educational research within postcolonial Africa: a critique of HIV/AIDS research in Botswana’, she describes how: “[her] journey into the empire and back”<sup>90</sup> opened her eyes to the self-defeating nature of research, however well-intentioned, when based in uneven distributions of epistemic status:

[I] wish to reflect and narrate on the lessons I learnt as an indigenous, Western educated intellectual, co-opted into the dominant First World epistemologies on HIV/AIDS and participating in the naming and description of the ‘other’. The discussion is based on a critique of research studies that I conducted, along with researchers from the so-called First World. I found myself troubled by the standard topics and language in the research on HIV/AIDS because they trivialized the core values that define my identity...<sup>91</sup>

Chilisa argues that the illness and disease experience of HIV/AIDS has been defined using normatively Western, biomedical frameworks, to the extent that “what falls outside the language of the [donors’] HIV/AIDS research is stigmatized, made invisible, labelled false, of less value or a handicap to addressing the spread of HIV/AIDS”.<sup>92</sup> Research subjects lack investment in a process in which their views are neither respected nor heard, and the needs of local communities thus predictably fail to be included in the final reports. In order to preserve the dominance of Western-defined categories of analysis and modes of inquiry, which entrenches the nineteenth-century dichotomy of European/Western as problem-solver and

<sup>89</sup> Bagele Chilisa, 'Educational research within postcolonial Africa' (2005), p. 663.

<sup>90</sup> Bagele Chilisa, 'Educational research within postcolonial Africa' (2005), p. 668.

<sup>91</sup> Ibid, p. 668.

<sup>92</sup> Ibid, p. 665.

‘native’ as problem, Chilisa finds that knowledges and experiences which could have improved mainstream efforts to reduce HIV incidence and prevalence are instead eradicated. These issues were writ large on an international stage in the early 2000s, when President Thabo Mbeki refused to align his position on HIV/AIDS with international medical consensus, arguing for greater attention to the social determinants of health that were particularly urgent factors in the spread of HIV/AIDS in poorer countries. Mbeki was accordingly characterised as an impediment to best practice and even held directly responsible for the deaths which occurred in South Africa during this period.

A question raised by this thesis is whether HIV/AIDS was seen to have the capacity to construct a spoiled identity not only for individuals but for nations: whether Sontag’s analysis of how stigma and metaphors function so that “the very reputation of the illness added to the suffering of those who already have it”<sup>93</sup> could be applied to South Africa as a whole. I suggest that while some of the texts discussed in the remainder of the thesis do not fit the conventional image of illness narrative, which usually takes the form of personal memoir or imaginative literature written from the point of view of a patient / person living with illness, they can be apprehended under my proposed term ‘disease narratives’, in that their intention is to make sense of the epidemic at the level of the social rather than individual body. As the epidemic – and blame - began to spread, some nations are known to have under-reported their statistics for fear of becoming symbolically tainted by the disease. In South Africa, much of what would transpire was influenced by President Thabo Mbeki’s resistance towards his people being maligned as, in his words, “germ carriers and human beings of a lower order [...] natural-born promiscuous, unique in the world, they proclaim that our continent is

<sup>93</sup> Susan Sontag, *AIDS and Its Metaphors* (1988), p. 12.

doomed to an inevitable mortal end”.<sup>94</sup> His efforts to resist this discourse and bring into existence a new, emancipatory one would prove in some ways tragically detrimental.

### **HIV/AIDS in the South African context: A chronology**

As a large and extremely heterogeneous country, with huge divergences in income, living standards, and enormous diversity of cultural tradition, spiritual practice and language, there could be no monolithic or even typical South African experience of HIV/AIDS. What follows is rather a broad chronological sketch of how HIV/AIDS was dealt with by successive regimes and administrations, the purpose of which is to set out the events which the rest of the thesis assumes awareness of and may refer to, and which may be unfamiliar to non-South African readers in particular. Again, this does not represent a comprehensive social analysis of these policies - a task which has been ably carried out by others<sup>95</sup> - and in deference to space gives only a relatively cursory version of developments. The contextualisation provided by this endeavour will however shed light on decisions that continue to resonate in contemporary texts, discourses and lived realities of HIV/AIDS in South Africa and provide a backdrop for the discussions constituting the remainder of the thesis.

#### ***Under Apartheid and the colonial encounter (-1994)***

The first cases of HIV in South Africa were diagnosed in 1982, when tests were carried out among a sample of white MSM in Johannesburg (eGoli), following reports of initial

<sup>94</sup> Thabo Mbeki cited in Didier Fassin, *When Bodies Remember* (2007), p. 313.

<sup>95</sup> See for example Pieter Fourie, *The Political Management of HIV/AIDS in South Africa: One Burden Too Many?* (Basingstoke: Palgrave Macmillan, 2006); Didier Fassin, *When Bodies Remember: Experiences and Politics of AIDS in South Africa* (Berkeley: University of California Press, 2007); Mark Gevisser, *Thabo Mbeki: The Dream Deferred* (Cape Town: Jonathan Ball Publishers SA, 2007); Pieter Fourie and Melissa Meyer, *The Politics of AIDS Denialism: South Africa's Failure to Respond* (New York, Routledge, 2016).

diagnoses from the United States. While the Department of Health appointed working groups to address the new disease, and in 1985 held a conference to address the potential threat that it posed,<sup>96</sup> the response of the Afrikaner National Party (NP) at state-level can be broadly characterised as inaction. In a 1992 review of the Party's handling of the epidemic, Yolanda Sadie and Maxi Schoeman protested that it was a struggle "to get HIV and AIDS on the policy agenda – even to get political scientists to write about AIDS in South Africa".<sup>97</sup> The puritanical Dutch Reformist Church government procrastinated installing an AIDS education programme in schools, and the few campaigns that were created were criticised as inappropriate and often offensive.<sup>98</sup> The anti-Apartheid academic boycott of South Africa and the fact that the Apartheid regime was expelled from the WHO at the time of the outbreak also exacerbated the matter, as the NP was therefore not required to participate in the procedures of the latter's Global Programme. When Apartheid ended in 1994, the adult prevalence of infection was estimated to amount to 7.6% of the population.<sup>99</sup>

The National Party's apathy towards HIV/AIDS cannot be separated from the country's past record, beginning with the proto-Apartheid forced removals and marginalisation by Dutch and British settlers that are "at the root" of the country's dysfunctional health system.<sup>100</sup> Two

<sup>96</sup> Iliffe, *The African AIDS epidemic* (2006), p. 67.

<sup>97</sup> Cited in Fourie, *The Political Management of AIDS in South Africa* (2006), p. 4.

<sup>98</sup> See for example Virginia van der Vleit, 'Apartheid and the Politics of AIDS' in *Global AIDS Policy*, ed. by Douglas A. Feldman (Westport: Bergin & Garvey, 1994). Van der Vleit summarises the controversies related to the NP's response (pp. 109-112) but, writing at the time of the transition, correctly saw that ultimately "the problems facing a state campaign in contemporary south Africa go beyond such specific criticisms and arise from the bedrock of apartheid's legacy [which] will affect not only black perceptions of state AIDS campaigns, but also right-wing constructions of the epidemic, and, in the final analysis, any alternative campaign devised by the anti-apartheid organisations themselves" (p. 112).

<sup>99</sup> For comparison, the average adult prevalence across Eastern and Southern Africa was 7.1% in 2015, while in Western Europe and North America it was 0.3%. (Global Burden of Disease Study 2016 cited in Max Roser and Hannah Ritchie 'HIV / AIDS' (2018) <<https://ourworldindata.org/hiv-aids>> [Accessed 7th September 2018]).

<sup>100</sup> Hoosen Coovadia, Rachel Jewkes, Peter Barron, David Sanders, Diane McIntyre, 'The health and health system of South Africa: historical roots of current public health challenges', *The Lancet*, 374, (2009), p. 817.

years after the National Party came to power, the Group Areas Act of 1950 became the first legislation passed to physically separate Black (African), Indian and Coloured people from Whites (Europeans) in South Africa. The implementation of such segregation practices is inextricable from the history of public health in the country, with medical doctors among the “foremost advocates of residential segregation”.<sup>101</sup> For example, the Public Health Act of 1883 included a provision which allowed for the establishment of ‘sanitary corridors and quarantines’ to prevent the spread of contagion. Following an outbreak of bubonic plague in Cape Town (eKapa) in 1901, this act was invoked to sanction an armed eviction of Black and Coloured people from the city to the first planned township, located at the sewage farm site of Uitvlugt (later known as Ndabeni) on the Cape Flats, even though, according to historian M.W. Swanson, “the number of Africans contracting the plague was less than either whites or coloureds”.<sup>102</sup> Predictably, the overcrowded and unsanitary conditions of the townships aggravated the spread of the disease, providing a post factum justification for their continuance.<sup>103</sup>

Access to health services was meanwhile concentrated in ‘white’, particularly urban, areas. As Giuliana Lund notes, in most countries affected by the colonial encounter, “the primary concern of tropical medicine in its early stages was the health of European soldiers, civil servants and settlers”, rather than local populations. Apartheid again exacerbated these

<sup>101</sup> Marks, Shula and Neil Andersson, ‘Epidemics and Social Control in 20th century South Africa’, *Radical Community Medicine*, 20 (Winter 1984–1985), p. 33.

<sup>102</sup> Maynard W. Swanson, ‘The sanitation syndrome: Bubonic plague and urban native policy in the Cape colony’, in *Segregation and Apartheid in Twentieth-Century South Africa*, ed. by William Beinart and Saul Dubow (New York: Routledge, 2003), p. 30.

<sup>103</sup> Although the outbreak was the public justification for these forced removals, records indicate that whites in Cape Town (eKapa) had begun to consider “establish[ing] an official ‘K\*\*\*\* location’” to limit black residents from as early as 1881 (Christopher Saunders et al, *Studies in the History of Cape Town*, 6 (1979), p.29). The hypocrisy of the public health rationale is further evidenced in the fact that white households continued to employ black servants, often on a live-in basis.

foundational inequities. Notably, the Public Health Amendment of 1897 was designed to entrench a fragmented and discriminatory system, with the result that by 1994, South Africa had fourteen separate health departments functioning independently. Another piece of colonial/Apartheid social planning that would have extreme repercussions for the HIV/AIDS epidemic in South Africa was the establishment of the migratory labour system. Mining drastically changed the country's economy after first diamonds were discovered in Kimberley in 1867, and then gold in the Witwatersrand in 1886. The industry of these precious stones and metals was made profitable through the manipulation of black male labour: Hoosen Coovadia et al describe how the "combination of coercive legislation, taxes, restrictions on access to land and means of production, and punitive control of desertions, served to enforce migration of male labourers to the towns".<sup>104</sup> This social arrangement would seriously undermine both the rural black agricultural economy and black family life, as well as becoming a "major determinant of subsequent disease patterns".<sup>105</sup> Tuberculosis was one disease that spread rapidly from the mines to the reserves, and, as an opportunistic infection, is one of the leading causes of death among PLWHA in South Africa today.<sup>106</sup>

In sub-Saharan Africa, unlike in Western Europe and North America where the virus was first identified, the main method of transmission is heterosexual. As described above, this led the medical community initially to distinguish two epidemiological patterns of AIDS, which

<sup>104</sup> Hoosen Coovadia et al, 'The health and health system of South Africa' (2009), p. 819.

<sup>105</sup> Ibid, p. 819.

<sup>106</sup> In South Africa, tuberculosis (TB) rates within the mining workforce are estimated at 2,500 – 3,000 cases per 100,000 individuals, representing 10 times the WHO threshold for a health emergency (The World Bank). TB remains the leading cause of death among people living with HIV, accounting for around one in three AIDS-related deaths (UNAIDS Fact Sheet 2017). On the more optimistic side, Francois Venter writes that the HIV/AIDS epidemic has prompted the world to face up to a "gross lack of ambition" in treating TB and transformed the research and policy agenda (Francois Venter, 'What have we learnt from the last ten years of ART?', South African Journal of HIV Medicine, 15(1), (2014), p. 39).

were dubbed ‘Western AIDS’ and ‘African AIDS’. It also meant that although the first case of HIV infection was diagnosed among black mineworker communities in 1983, “for the first eight years [in South Africa], the epidemic appeared as a primarily gay, white disease”.<sup>107</sup> Unsurprisingly, the NP showed little motivation to address AIDS in black communities. Early government-sponsored campaigns were nonetheless filled with assumptions regarding the disease vectors of the epidemic that were widely criticised as being both homophobic and racist.<sup>108</sup> These demeaning stereotypes would lay the groundwork for many people in South Africa (arguably including President Mbeki) to reject the official messaging on HIV/AIDS, in ways that ranged from contesting its biomedical explanation to entertaining conspiracy theories that HIV was “invented in the ‘laboratories of the military-industrial complex of the West’”.<sup>109</sup>

What steps *did* the Apartheid government take to combat the epidemic? The Presidents that presided over the first years of the epidemic, Pieter Willem Botha and Frederik de Klerk, made no public statements about HIV/AIDS. From 1989, the NGO sector began receiving

<sup>107</sup> Alan Whiteside, ‘Foreword’, in Pieter Fourie, *The Political Management of HIV/AIDS: One Burden Too Many?* (Hampshire and New York: Palgrave), p. xvi.

<sup>108</sup> Virginia van der Vleit, ‘Apartheid and the Politics of AIDS’ (1994).

<sup>109</sup> Mark Gevisser, *Thabo Mbeki: The Dream Deferred* (Cape Town: Jonathan Ball Publishers SA, 2007), p. 731. Such theories were particularly hard to dislodge in South Africa given the Apartheid regime’s known use of chemical and biological weapons, their hostility and paranoia towards the ‘swart gevaar’ - indeed, one Conservative Party MP opined openly in Parliament that “if AIDS stops black population growth, it would be like Father Christmas” (Republic of South Africa, *Debates of Parliament*, (18 May 1990), 9797) - and their attempts to mobilise the epidemic as a scientific argument against ending racial segregation in the country (Thomas Long, *AIDS and American Apocalypticism – The Cultural Semiotics of an Epidemic* (Albany: State University of New York Press, 2005), p.184, cited in Lizzy Attree, *Blood on the Page: Interviews with African authors writing about HIV/AIDS* (Cambridge: Cambridge Scholars Publishing, 2010), p. 6). Conspiracy theories relating to HIV/AIDS in general tend to expose a wider distrust towards authorities and have also been found to be salient among African American demographics, reflecting the history of abuses committed towards that group such as non-consensual medical experimentation on human subjects and sterilisation. Research published in the *American Journal of Public Health* in January 2015 argued that because these narratives are the product of this history, people who believe them are unlikely to be convinced by “evidence they deem untrustworthy” (Jacob Heller, ‘Rumors and Realities: Making Sense of HIV/AIDS Conspiracy Narratives and Contemporary Legends’, *American Journal of Public Health* (2015), doi: 10.2105/AJPH.2014.302284).

support from the United States' Centres for Diseases Control and Prevention (CDC 2013), although "given the limited knowledge regarding HIV transmission dynamics, the mainstay of the response during the 1980s and 1990s was the provision of condoms and a 'safe-sex' education strategy hampered by stigma [and] fear",<sup>110</sup> which did not address the structural drivers of infection specific to the country. In response to the inadequacy of government intervention, South Africa saw "the mobilisation of three key sets of actors: the private sector, the biomedical community and the legal fraternity"<sup>111</sup> in the HIV/AIDS arena, and this enhanced agency of civil society would prove to later have weighty repercussions for how the epidemic played out in the new South Africa.

### ***Under President Nelson Mandela (1994 – 1999)***

On 27 April 1994, the country's historic first universal election marked the transition from the Apartheid regime to a multi-racial, democratic nation, governed by Nelson Mandela's African National Congress (ANC) party. The ANC showed an impressive level of dedication to the challenge of HIV/AIDS: from exile, the party had already begun to create policies in readiness to govern the country, and in 1990 they held a joint conference in Maputo with the National Department of Health to address the HIV/AIDS epidemic. At this occasion, the leader of uMkhonto weSizwe (MK)<sup>112</sup> Chris Hani, declared:

<sup>110</sup> N.P. Simelela and W.D.F. Venter, 'A brief history of South Africa's response to AIDS', *South African Medical Journal*, 104 (3), p. 249.

<sup>111</sup> Pieter Fourie, *The Political Management of HIV/AIDS in South Africa* (2006), p. 178.

<sup>112</sup> uMkhonto weSizwe (MK) was the armed branch of the ANC, co-founded by Nelson Mandela in the wake of the Sharpsville Massacre of March 1960. In exile from South Africa, MK troops had been barracked in countries struck by AIDS throughout the 1980s, so Hani spoke from first-hand experience of the epidemic's reality and tragic implications. Former Director-General to the Presidency Frank Chikane records that "those who returned from exile [many in tropical African countries where the epidemic had manifested earlier] had a better sense of the challenge of HIV and AIDS than those of us who were in the country" (Frank Chikane, *The Things That Could Not Be Said: From AIDS to Zimbabwe* (Johannesburg: Picador Africa, 2013), p. 257). Hani was assassinated in 1993 by a far-right anti-communist, and some have conjectured had this not been the case, he may have succeeded Mandela instead of Mbeki and implemented very different HIV/AIDS policies (see for example Didier Fassin, *When Bodies Remember* (2007)).



We cannot afford to allow the AIDS epidemic to ruin the realization of our dreams. Existing statistics indicate that we are still at the beginning of this epidemic in our country.

Unattended, however, this will result in untold damage and suffering by the end of the century.<sup>113</sup>

When political negotiations began between the ANC and the departing National Party in the early 1990s, the establishment of a National AIDS Coordinating Organisation were also discussed. As a result, within months of the 1994 elections, the government was able to adopt a National AIDS Plan (NAP) that had been agreed upon by multiple stakeholders. The plan focused on prevention of HIV transmission through public education campaigns; appropriate care, support and treatment for the infected; and the mobilisation of resources at local, provincial, national and international levels. Pieter Fourie records that a “more politically correct and seemingly socially appropriate policy could hardly be imagined”.<sup>114</sup>

The initial optimism produced by the Plan would however quickly fade. By the following year, it was becoming clear that there was a “strong disconnect between the development of policy at the national level and the implementation of that policy at the local and provincial level”.<sup>115</sup> Because the NAP had been negotiated before the changeover in power, it was conceived without full awareness of the bureaucratic constraints that would be involved in putting the policy into practice. Worse, a series of embarrassing high-profile decisions typified what appeared to be an increasingly scattershot approach to policy-making, and the accompanying scandals created a wedge between government and civil society that

<sup>113</sup> Chris Hani cited in Didier Fassin, *When Bodies Remember* (2007), p. 1.

<sup>114</sup> Pieter Fourie, *The Political Management of HIV/AIDS* (2006), p. 109.

<sup>115</sup> Jeremy Youde, ‘Ideology’s role in AIDS policies in Uganda and South Africa’, *Global Health Governance*, 1(1), (2007), p. 10.

“solidified a defensiveness in the government, henceforth rendering AIDS policymaking reactive rather than visionary or proactive”.<sup>116</sup>

In August 1995, the Department of Health (under Minister of Health Dr Nkosikasi Dlamini-Zuma) commissioned an educational play titled *Sarafina II*, a sequel to the popular anti-Apartheid musical of the same name.<sup>117</sup> The script prompted widespread objections, as did the choice to spend R14 million – around one fifth of the AIDS budget – on a single initiative. The play was halted amid a storm of skirmishes, and finally never produced. Close on its heels was the controversy over Virodene, a supposed AIDS drug that was ‘invented’ by a scientist named Olga Visser at the University of Pretoria, who along with her businessman husband, had carried out several unauthorised trials on human subjects. Despite being instructed by the MCC to close down their research, the Vissers were permitted to brief the cabinet on their preliminary findings in January 1997. Virodene ultimately turned out to have no antiretroviral effects.<sup>118</sup> Mandela would later publicly express regret over his handling of the epidemic, calling *Sarafina II* in particular one of the major failings of his term.<sup>119</sup>

<sup>116</sup> Pieter Fourie, *The Political Mismanagement of HIV/AIDS* (2006), 124.

<sup>117</sup> Mbongeni Ngema, *Sarafina!* in *Best of Mbongeni Ngema: An Anthology* (Johannesburg: Skotaville, 1995).

<sup>118</sup> Various sources have traced the origin of Mbeki’s shifting views, from a straightforward orthodox approach to tackling HIV/AIDS to a more sceptical one, to this time: “It is known that Mbeki shifted his views about HIV during the Virodene controversy. During this period, he began to see HIV as one of the causes of AIDS rather than the sole cause” (Frank Chikane, *The Things That Could Not Be Said* (2013), p. 276). Seth Kalichman state that a common feature of conspiracy-prone thinking is “an actual experience that validates a worldview. For Mbeki, his central involvement in the infamous Virodene scandal may very well serve as just such an event. [It] may have fuelled a sense of mistrust in medicines and medical authorities” (Nicoli Nattrass and Seth C. Kalichman, ‘The Politics and Psychology of AIDS Denialism’, in *HIV/AIDS in South Africa 25 Years On: Psychosocial Perspectives*, ed. by Poul Rohleder, Leslie Swartz, Seth C. Kalichman and Leickness Chisamu Simbayi (Berlin/Heidelberg, Springer Science & Business Media 2009), p. 132).

<sup>119</sup> Nicoli Nattrass, *The Moral Economy of AIDS in South Africa* (Cambridge: Cambridge University Press, 2004), p. 45.

During his five years as President, the number of people infected with HIV in South Africa increased six hundred-fold, from five thousand to three million; the mean life expectancy of the population also plummeted. It should be noted that these statistics are linked to the increase in testing of the general population after 1994, leading to inevitably greater visibility. Nevertheless, Mandela certainly could have used his momentous moral authority more forcefully on the subject of AIDS while in power – John Iliffe records that after “a bold speech in 1991 had angered a rural audience, [Mandela said that] in the 1994 election ‘[he] wanted to win and [so he] didn’t talk about AIDS’ and then ‘had not time to concentrate on the issue’ while President”.<sup>120</sup> After stepping down he would become more vocal on the topic, including his public announcement in 2005 that his son Makgatho Mandela had passed away from AIDS at the age of 54, explicitly addressed taboos around the disease in South Africa: “Let us give publicity to HIV/AIDS and not hide it, because [that is] the only way to make it appear like a normal illness”.<sup>121</sup> During his administration, however, given his fragile health from his advanced age and the 27 years of imprisonment he had endured on Robben Island, most of the operations and policy decisions were delegated to his Deputy President Thabo Mbeki. Mbeki had likewise been placed personally in charge of the AIDS portfolio from the first meeting “to make sure that there was leadership at a presidential level”<sup>122</sup> and perhaps “compensating for Mandela’s disregard for – or, at least – discomfort with the issue”.<sup>123</sup>

<sup>120</sup> Mbeki quoted in John Iliffe, *The African AIDS Epidemic* (2006), p. 67.

<sup>121</sup> Michael Wines, 'Mandela, Anti-AIDS Crusader, Says Son Died of Disease', *The New York Times*, January 7, 2005.

<sup>122</sup> Frank Chikane, *The Things That Could Not Be Said* (2013), p. 257.

<sup>123</sup> Mark Gevisser, *Thabo Mbeki* (2007), p. 721. Some have suggested that Mandela de-emphasised the epidemic in part due to his wish to emphasise nation-building and reconciliation between the racial groups. Others have noted Mandela’s reluctance when it came to openly discussing sexual matters, reflecting the discretion and reserve typical of Xhosa culture, in contrast to the “exposure to sexual mores so vastly different from those whence he came” (Ibid, p. 189) that Mbeki experienced in his time at the University of Sussex in the sexually liberated 1960s.

It was in this role that Mbeki began to review literature about the drugs recommended by international health-governing bodies and, controversially, to query their appropriateness for South Africa. Initially, what was at stake was an economic issue: the feasibility and sustainability of providing ARVs at the necessary scale. Highly active antiretroviral treatment (HAART) had first been presented as a viable treatment for PLWHA at the 11<sup>th</sup> International AIDS Conference in Vancouver in 1996. Yet the annual cost of ten to fifteen thousand US dollars per patient was clearly prohibitive for less affluent nations, particularly as many were confronted with far larger infected populations. Consequently, as the virus began to be halted in the social body of Global North nations, poorer nations continued to suffer dismayingly high death tolls from AIDS and rising rates of infection. To make matters worse, South Africa's existing procurement agreements, which had been negotiated by the National Party, meant that it had some of the highest drug prices in the world.<sup>124</sup> While the South African health system was "well-resourced compared with that for other middle-income countries",<sup>125</sup> its high-level medical infrastructure had been designed only for a minority making up less than 20% of the population. Providing ARVs therefore required a range of additional measures including, but not limited to, the training of medical personnel, public communication and health education, and the building of new clinics, hospitals and setting up of supply chains. The cost of reforms needed in healthcare was daunting for a state that had been left close to bankrupt by the recent years of conflict, and was at the same time attempting to effect a systematic transformation of all aspects of its constitutional

<sup>124</sup> Nkosazana Dlamini-Zuma, 'South Africa's New National Drug Policy', *Journal of Public Health Policy*, 18(1), (1997).

<sup>125</sup> Hoosen Coovadia et al, 'The health and health system of South Africa' (2009), p. 828.

governance.<sup>126</sup> Pieter Fourie has described HIV/AIDS ‘one burden too many’ for South Africa.<sup>127</sup>

These challenges withstanding, the government made several significant advances in the field of health provision. In keeping with Section 27 of the new Constitution’s promise that “everyone has the right to have access to healthcare services”,<sup>128</sup> free medical services were extended first to children under six years old and all pregnant women who could not afford to pay themselves. In order to procure the medicines - including ARVs - needed, the ANC also introduced a bold set of legislation. The Medicines and Related Substances Control Amendment Bill (1996) would allow South Africa to obtain more affordable versions of existing drugs through parallel importing and compulsory licencing. Global pharmaceutical companies however refused to alter their agreements, fearful of the precedent this would set, and went as far as to file intellectual property lawsuits against the ANC government. The United States’ government itself threatened South Africa with crippling economic sanctions, placing the nation temporarily on the international terrorism watch list. Eventually, however, Big Pharma gave into pressure from global activists and the resulting Medicines and Related Substances Control Amendment Act (1997) represented a victory of underappreciated magnitude. Indeed, the Ugandan judge Barney Afako says that “securing cheaper

<sup>126</sup> Following President P.W. Botha’s ‘Rubicon’ speech on 15 August 1985, in which he announced that reforms to the Apartheid system would not take place, the Rand devalued overnight by more than 100% (cf. Laurence Harris, ‘South Africa’s external debt crisis’, *Third World Quarterly*, 8(3), (1986), 794-817. According to figures estimated by the Jubilee 2000 Campaign, the ANC inherited debts of R86.7 billion upon its ascent to power in 1994 (Cited in *The Economist*, ‘Unforgivable’, <<https://www.economist.com/finance-and-economics/1999/04/22/unforgivable>> [Accessed 3<sup>rd</sup> September 2018]).

<sup>127</sup> Pieter Fourie, *The Political Management of HIV/AIDS in South Africa* (2006).

<sup>128</sup> Republic of South Africa, ‘The Constitution of the Republic of South Africa’ (1996).

antiretroviral drugs [was] arguably the single intervention with the furthest reaching consequences in the fight against AIDS on the continent”.<sup>129</sup>

The triumph of passing the Act brought government and civil society together to celebrate on the steps of Pretoria High Court. However, this unity again quickly dissipated. Activists began petitioning the government to take advantage of the new legislature by providing an antiretroviral drug called Azidothymidine (AZT), which had been shown to be effective in preventing mother-to-child transmission in pregnant women, but the government refused, citing budget restraints and toxic side-effects.<sup>130</sup> On 10 December (International Human Rights Day) of 1998, the HIV-positive activist and struggle veteran Zackie Achmat launched the Treatment Action Campaign (TAC), a consortium of grassroots organisations which insisted that the government was constitutionally obliged to provide ARV drugs. The TAC is widely acknowledged as one of the most important civil society organisations active on AIDS worldwide, and continues to organise, inform and litigate on behalf of users of the public healthcare system in South Africa. In 1999, Achmat famously pledged to refrain from taking his life-saving medications until a national treatment plan was rolled out to all South African citizens who needed them.

<sup>129</sup> Barney Afako, ‘Foreword’, in *The Thabo Mbeki I Know*, ed. Sifiso Mxolisi Ndlovu and Miranda Strydom (Johannesburg: Picador 2016), pp. xvi.

<sup>130</sup> AIDS Weekly, ‘South Africa says it can’t afford anti-AIDS drug AZT’ (1999) <<https://www.ncbi.nlm.nih.gov/pubmed/12349345>> [Accessed 8th September 2018]



Figure 1: Nelson Mandela with TAC founder Zackie Achmat, both wearing the distinctive TAC “HIV Positive” t-shirts, in 2002.

(Photograph: AFP)



Figure 2: Protestors on a TAC march (26 November 2001) hold posters reading “Hope, Information, Victory” and “Thabo Your Ideas are Toxic”. (Photograph: Anna Zieminski, Getty Images)

### ***Under President Thabo Mbeki (1999 – 2008)***

On the 16th June 1999, Thabo Mbeki formally succeeded Nelson Mandela as the nation’s second democratically elected President, after the ANC had won an even more resounding victory in that year’s national elections. From this point, he would become more and more identified as the face of the government’s policy on HIV/AIDS. In October 1999, just a few months after becoming President, he made a speech at the National Council of Provinces which publicly challenged conventional wisdom around HIV/AIDS for the first time and was later pinpointed as “the speech that sounded the beginning of Mbeki’s ‘denialism’”.<sup>131</sup> The

<sup>131</sup> Frank Chikane, *The Things That Could Not Be Said* (2013), p. 261.

furor reached new audiences in July 2000, when the city of Durban (eThekweni) in Kwa-Zulu Natal hosted the 13th International AIDS Conference. This was the first occasion that the biannual conference had been held in the Global South in its fifteen-year history – a clear oversight given the disproportionate devastation the epidemic was wreaking on poorer nations. As such, it could have symbolized a new moment of global collaboration; instead, it became notorious for Mbeki's clash with the international scientific community over its approach to the epidemic. His opening speech to the delegates (many of whom had threatened to boycott the conference because of his opinions) emphasized the intersection between AIDS deaths and structural conditions of poverty, framing it as an issue of economic development as well as one of public health.

Through the event's reporting in national and international media, the speech cemented Mbeki's reputation as a 'dissident', entrenching in public knowledge that he did not believe that there was any causal link between contracting the HIV virus and dying with AIDS. In an article titled 'Mbeki Speech Angers AIDS Researchers' (2000) in *Science* magazine, the journalist reported that "thousands of researchers packed into Kingsmead Stadium hop[ing] he would say three simple words: HIV causes AIDS. He didn't",<sup>132</sup> while in the *Guardian's* 'Mbeki insists poverty causes Aids', he was described as "[a]n unrepentant Thabo Mbeki, president of South Africa [who] yesterday refused to bow to pressure from international scientists and used his speech [...] to blame the Aids epidemic devastating the continent on poverty rather than the HIV virus".<sup>133</sup> The medical anthropologist Paul Farmer stands out as

<sup>132</sup> Jon Cohen, 'Mbeki Speech Angers AIDS Researchers', <http://www.sciencemag.org/news/2000/07/mbeki-speech-angers-aids-researchers/> [Accessed 28<sup>th</sup> August 2018].

<sup>133</sup> Sarah Boseley, 'Mbeki insists poverty causes Aids', *The Guardian*, 10 July 2000.



one of the few diverging voices, having attended the conference in part “to hear the man for myself”:

Mbeki’s message was this: poverty and social inequality serve as HIV’s most potent co-factors, and any effort to address this disease in Africa must embrace a broader conception of disease causation. This is precisely the point many of us have tried to make, and though our views have not always been welcome, we haven’t been branded as AIDS heretics. And Mbeki consistently referred to the disease as ‘HIV/AIDS,’ clearly making the connection between the virus and the syndrome.<sup>134</sup>

Mbeki’s obdurate personality undeniably fuelled the already bitter conflict. His own keynote speech was followed by a speech given by a twelve-year-old HIV-positive boy named Nkosi Johnson, entreating Mbeki and his government to provide ARVs to South African babies infected with the virus. While most of the audience were moved by the terminally-ill child’s speech, Mbeki stood up and left the venue while Johnson was still speaking, a gesture that was taken to reflect his unfeelingness towards PLWHA in general. In addition, when asked about the Durban Declaration, a document signed by over 5000 international scientists at the conference requesting that Mbeki change his views on HIV/AIDS, his spokesman Parks Mankahlana bluntly told reporters it would find its way to the ‘dustbin’.<sup>135</sup> South Africa’s new government found itself internationally censured for its AIDS policy and Frank Chikane, the Director General to the Presidency at that time, recalls that:

the period 2000 to 2002 felt like a war [...] The fire was like heat-seeking missiles.

Everywhere Mbeki went for any reason, his business was diverted towards the HIV/AIDS

<sup>134</sup> Paul Farmer, ‘AIDS Heretic’ <https://newint.org/features/2001/01/05/heretic>, [Accessed 28<sup>th</sup> August 2018]

<sup>135</sup> Pat Sidley, ‘Mbeki dismisses “Durban Declaration”’, *BMJ*, 321(7253), p. 67.

controversy. No matter what subject he was dealing with, the discussions always ended up being a discussion about HIV and AIDS.<sup>136</sup>

In the final event, the TAC forced the hand of the government by bringing a landmark case against them in the Pretoria High Court in 2001, which was upheld the following year by the Constitutional Court. The ANC was ordered to provide Nevirapine to all HIV-positive women and their new-borns, and in the same year, the party concluded that Mbeki should withdraw his views on AIDS from the public arena and represent only the governmental stance. After long discussions, Mbeki finally agreed to refrain from making further personal statements about HIV/AIDS in public, instead stating only the agreed policy position of the ANC. In 2003, the government released their new National Policy on HIV/AIDS, surprising many with its announcement that ARVs would be made available through the public health service. Although the roll-out did not fully occur until 2005, take-up has been encouraging, with 4.4 million people currently taking ARVs in South Africa (62% of estimated PLWHA). In 2006, the Cabinet signed off on the 'HIV & AIDS and STI Strategic Plan for South Africa 2007 – 2011', which was prepared by the South African National AIDS Council (SANAC) in a "laborious, politically charged but widely consultative process"<sup>137</sup> and internationally hailed as an example of good policy.<sup>138</sup> Shortly afterwards, however, at the 2007 ANC Conference at Polokwane, Mbeki would be forced to resign from the Presidency by his former Deputy Jacob Zuma. Mbeki's NEC had persuaded him to take a step back from AIDS policy out of fear that foreign powers would engineer a 'regime change', ultimately, however, he was unseated by a different power fault-line altogether.

<sup>136</sup> Frank Chikane, *The Things That Could Not Be Said* (2013), p. 287.

<sup>137</sup> N. P. Simelela et al, 'A brief history of South Africa's response to AIDS' (2014), p. 250.

<sup>138</sup> Hoosen Coovadia et al, 'The health and health system of South Africa' (2009), p. 828.

### ***Under President Jacob Zuma (2009 – 2018) and Cyril Ramaphosa (2018 – present)***

Following a short period in which Kgalema Motlanthe held office as interim President, Jacob Gedleyihlekisa Zuma was elected into office in the general elections of April 2009. Like his Presidential predecessors, Zuma has anti-Apartheid struggle credentials: he spent ten years imprisoned on Robben Island after being arrested at the age of 21 for conspiring to overthrow the NP government. After his release in 1973, he went into exile in Zambia and forged a close relationship with Thabo Mbeki during this time. During the late 1980s, Zuma ran the ANC's intelligence operations, and when the organisation's banning was lifted in 1990 was one of the first members to return to South Africa to begin the negotiations process. Following the ANC's victory in the country's first democratic elections in 1994, he became a Member of the Executive Council for his home province of KwaZulu-Natal and in June 1999 was chosen by Mbeki to be his Deputy Prime Minister.

Both before and throughout his Presidency, Zuma found himself at the centre of numerous controversies, surviving a total of six votes of No Confidence during his nine years in power: Sizwe Mpofu-Walsh writes that "his battle with the law is the leitmotif of South Africa's second decade of democracy".<sup>139</sup> Amidst these crises was his own problematic contribution to the AIDS discourse in South Africa. In 2005, a rape case was brought against him by an accuser who was known only to the public as "Khwezi", and who has, posthumously, now been named as AIDS activist Fezikile Ntsukela Kuzwayo. Zuma testified that he had engaged in consensual sex with Kuzwayo and was pronounced innocent in the trial. He also declared that despite knowing Kuzwayo was HIV positive, he had not used a condom but had taken a

<sup>139</sup> Sizwe Mpofu-Walsh, *Democracy and Delusion: 10 Myths in South Africa* (Tafelberg 2017), Location 902, Kindle edition.

shower afterwards to “minimise the risk of contracting” the virus.<sup>140</sup> Naturally, beyond the egregiousness of the allegations and their implications for women’s rights in the country, the misinformation around the virus was of grave concern to activists and public health professionals.



Figure 3: ‘Erasing the Aids message’. A Zapiro cartoon (2006) shows Jacob Zuma holding the ‘ABC of HIV prevention’, with the words of his AIDS message being washed away by a shower.

Against these discouraging expectations, Zuma began his tenure by acknowledging HIV/AIDS as one of the most important challenges facing the country and announcing a major overhaul of its HIV/AIDS policies. Under his newly appointed Health Minister Dr Aaron Motsoaledi, the roll-out of ARV treatment was increased drastically, accompanied by a widespread HIV counselling and testing campaign. In 2009, fewer than two million HIV/AIDS tests had been conducted in state facilities, a figure which rose to 14 million by 2016. Yearly mother-to-child transmissions (MTCT) have fallen from 70,000 in 2004 to below 6000 at time of writing, and the life expectancy of South Africans has improved from 55 years in 2002 to just over 62. (In 1994, the first year of democracy, average life

<sup>140</sup> BBC, ‘SA’s Zuma ‘showered to avoid HIV’’, <<http://news.bbc.co.uk/1/hi/world/africa/4879822.stm>>, [Accessed 28th August 2018]

expectancy was 61 years). The government, which was spending \$1.2 billion a year on HIV/AIDS in 2016, is adding \$65 million annually through 2019. In July 2016, Durban (eThekweni) hosted the International AIDS Conference for the second time. The atmosphere at the conference was reflective of the progress made both in South Africa and globally, although the TAC maintained pressure on the government and the attending international bodies by leading a march on the 18th July to highlight the ground still left to cover: almost half of the infected population in South Africa remains untreated, and incidence is still high with 270,000 new infections in 2016.<sup>141</sup> Reforms in the healthcare sector are still overdue, with poor supply chains meaning that ‘stock-outs’ present a huge problem for patients who are unable to obtain their medication on time. Meeting the UNAIDS 90-90-90 target is forecasted to require an addition US\$8 billion over the next five years. Analysts have also noted that the relative stabilisation of national infection rates during Zuma’s regime is not directly correlated to the change of administration but should also be understood “as a consequence of the natural attrition of the disease: ‘saturation point’, in the parlance of epidemiologists”.<sup>142</sup>

AIDS was moreover one of the more successful areas of Zuma’s administration. Since Mbeki’s removal from power the economy has stalled, with South Africa now the world’s most unequal economy in the world and unemployment rising in the decade since 2006.<sup>143</sup> The fact that living conditions have improved so little for many since 1994 has produced rising impatience and disillusionment with the once-invulnerable ANC party and its promises

<sup>141</sup> UNAIDS, ‘Ending AIDS: Progress towards 90-90-90 targets’ (2017).  
<[http://www.unaids.org/en/resources/documents/2017/20170720\\_Global\\_AIDS\\_update\\_2017](http://www.unaids.org/en/resources/documents/2017/20170720_Global_AIDS_update_2017)> [Accessed 7<sup>th</sup> September 2018]

<sup>142</sup> Pieter Fourie, *The Political Management of AIDS in South Africa* (2006), pp. 5-6.

<sup>143</sup> Sizwe Mpfu Walsh, *Democracy and Delusion* (2017).

of a better life for all. Achille Mbembe asserted in 2015, at the height of the #FeesMustFall student protests, that “a new cultural temperament is gradually engulfing post-Apartheid urban South Africa [and] the relative cultural hegemony the ANC exercised on black South African imagination ... is waning”.<sup>144</sup> This was borne out in the August 2016 local elections, in which the government lost control of multiple major municipalities including the cities of Tshwane (Pretoria) and Johannesburg (eGoli). Widely seen as a turning point in the country’s political landscape, both the Democratic Alliance (DA) opposition party and the newcomer splinter party Economic Freedom Fighters (EFF) gained significant support. The ANC found itself under pressure to unify their party in the hopes of retaining their majority in the 2019 general elections.

In the late evening of 14 February 2018, more than a year before the end of his term, Jacob Zuma resigned as President after being recalled through a series of electoral events that echoed his own assumption of the leadership role from Mbeki. In doing so, he avoided having to face a seventh motion of No Confidence in parliament, which analysts predicted he would not have survived. His successor, Cyril Ramaphosa, was elected ANC President in December 2017 over the other candidate, Zuma’s ex-wife Nkosazana Dlamini-Zuma (who had been the Health Minister under Mandela’s administration that oversaw the Sarafina II scandal). As is traditional for the Deputy President, Ramaphosa served as Chairperson of the South African National AIDS Council (SANAC) since his appointment as Motlanthe’s successor in March 2014, in which role he oversaw the current National Strategic Plan (NSP) on HIV, TB and STIs 2017-2022, which was published in March 2017. The TAC has issued a

<sup>144</sup> Achille Mbembe, ‘Achille Mbembe on The State of South African Political Life’ (2015), <<https://africasacountry.com/2015/09/achille-mbembe-on-the-state-of-south-african-politics/>> [Accessed 28<sup>th</sup> August 2018]

statement welcoming Zuma's resignation, asserting that the corruption and mismanagement that flourished during his years in power had seriously "compromised service delivery to people dependent on the public healthcare system", and expressing hope that their experiences of "constructive engagements" with Ramaphosa during his tenure would continue.<sup>145</sup>

## **Conclusion and outline of chapters**

As can be seen, the 'narrative' of the HIV/AIDS epidemic in South Africa is intricately plotted, and crucially, is in many ways intertwined with the narrative of the political development of the new nation. As the anti-Apartheid struggle dominated South African life during the 1980s and first half of the 1990s, the epidemic was only fully identified as a political challenge and priority after democratic independence in 1994. At the outset of the epidemic, many predicted that African governments would be completely destabilised by the impact of the disease.<sup>146</sup> While the feared outcome did not manifest in South Africa, in many ways the political treatment of the epidemic has been discursively conflated with the political and ideological health of the country. In subsequent chapters, the epidemic is taken as emblematic or symptomatic of the quality of leadership, freedom of expression, economic inequality, transformation and relations between genders, races and ethnically and epistemically differing communities within South Africa. Andrew van der Vlies argues that a distinctive "profound experience of disappointment" emanates from post-Apartheid South

<sup>145</sup> TAC, 'TAC Welcomes Resignation of Former President Zuma – Urges New Acting President Ramaphosa To Initiate Bold Reforms' (15 February 2018) < <https://tac.org.za/news/tac-welcomes-resignation-of-former-president-zuma-urges-new-acting-president-ramaphosa-to-initiate-bold-reforms/> > [Accessed 28<sup>th</sup> August 2018]

<sup>146</sup> See for example Alex de Waal, *AIDS and Power: Why there is no political crisis in Africa – yet* (London: Zed Books, 2006); Tom Lodge, 'The politics of HIV/AIDS in South Africa: government action and public response', *Third World Quarterly*, 36(8), 2015, <https://doi.org/10.1080/01436597.2015.1037387>.

African writing, which registers how the unfulfilled dream of equality and transformation shadows contemporary life.<sup>147</sup> Through the economic, social and existential actualities of the country, the impact of HIV/AIDS is palpable even where it may appear to go unstated. The remainder of the thesis examines ways in which texts that have emerged in order to make sense of, represent or analyse HIV/AIDS as a social phenomenon in South Africa have interpreted the epidemic as revealing of the state of the polis.

Chapter Two sketches ways in which the figure of Thabo Mbeki has come to personify the disappointments and outcomes of the South African AIDS story, reflecting on how various biographical and fictional accounts represent his character in direct relation to the epidemic. The chronological overlap of Mbeki's tenure and the height of the epidemic brought about intersections where the two 'stories' acted upon one another; Mbeki's biographical experiences and beliefs can be seen to have influenced how the epidemic was tackled, while the controversies that surfaced around HIV/AIDS treatment in turn came to centre upon Mbeki's personality. Efforts to re-appraise and document Mbeki's role in relation to the HIV/AIDS crisis are seen to reflect changing attitudes towards both his predecessor Nelson Mandela and his successor Jacob Zuma, as the hopefulness of the early post-transition years was replaced by disillusionment and cynicism. South African writers' focus on the implications of these decisions can be viewed as processing AIDS as a social phenomenon, a mirror onto the state of the nation and its political culture, forming what I have called 'disease narratives' as opposed to the concept of 'illness narratives'.<sup>148</sup> It also views the controversial opinions furthered by Mbeki and the ANC in light of how epistemic injustices

<sup>147</sup> Andrew van der Vlies, *Present Imperfect: Contemporary South African Writing* (Oxford: Oxford University Press, 2017), p. vii.

<sup>148</sup> Arthur Kleinman, *The Illness Narratives; Suffering, Healing and the Human Condition* (New York: Basic Books, c.1988)



which skew processes of global knowledge production in favour of the West / Global North contributed to the way these events unfolded.

In Chapter Three, I probe the idea of ‘silence’ as it has been invoked in relation to HIV/AIDS in South Africa and with particular reference to a perceived lack of literary works confronting the topic. The refrain that South African writers, particularly black writers, have been reproachably silent on the subject of HIV/AIDS is reframed within wider patterns of epistemic injustice faced by African people and societies. I argue that certain ‘silences’ are discursively constructed through the de-legitimation or erasure of those knowledges, and disguise where in reality a multitude of ‘hidden transcripts’ flourish. The chapter explores the interplay of these issues with accepted ideas about the function of literature and conceptions of the writer’s role and responsibility, and how writers and literary critics from South Africa have responded to these discursive pressures. The reception of these texts is considered to illuminate the power relations between global AIDS-related discourses and processes of knowledge production in and about the postcolony. Expanding on connections between HIV/AIDS and world literature or ‘Englishes’ as phenomena acting on and through the energies of globalisation, it concludes that reading illness narratives from outside the centre must not simply follow an ‘add diversity’ approach, and thus has implications for methodology within global literature studies.

In Chapter Four, I read two recent contemporary South African novels, Masande Ntshanga’s debut novel *The Reactive* and Imraan Coovadia’s *Tales of the Metric System*. Both published in 2014, they post-date the ‘silence’ debates that are centred in the previous chapter, and I read them in relation rather to shifting attitudes towards the promises and potential of the ‘new’ South Africa and the ANC. In both novels, Mbeki’s policy decisions loom large, and as

such the presentation of HIV/AIDS as a social crisis reflects back on the country's governance and charts the course on which it was travelling in the early decades of the millennium. Coovadia's novel sets the crisis most explicitly in a political context, as discussed briefly in the previous chapter; here I examine the ways in which he presents the fraught process of knowledge production at the intersection of medicine, politics and money, which is enacted on the bodies of those without those powers. Of interest in this chapter is the fact that both novels use ART as a plot device, signalling how the affordability and availability of treatment, and the ways in which they expose ongoing systematic inequalities and oppressions, intersect with the writers' perception of the economic and psychic contradictions of the new nation. Finally, drawing on Havi Carel's work on illness and phenomenology to consider *The Reactive's* particular effectiveness, I argue that Ntshanga's text deftly presents HIV/AIDS in a way that refuses to indulge established moral and metaphorical trappings, which simultaneously implicitly challenges the metanarrative that there is a prescribed way in which literature must deal with social issues.

Chapter Five reflects on how the emergence of a strong non-fiction tradition in South Africa in the post-Apartheid moment produced narratives that consciously sought to align an understanding of the HIV/AIDS epidemic with the developing narrative of the state of the post-Apartheid nation.<sup>149</sup> I work at the genre's eroding boundaries with an analysis of Jonny Steinberg's *Sizwe's Test* (2007) – published in the UK as *Three Letter Plague* (2009) – and

<sup>149</sup> HIV/AIDS formed an ambivalent foil to Apartheid in a narrative sense. The novelist Phaswane Mpe wrote that he engaged the subject in part as an “antidote to those who think that South Africans have nothing to write about in the post-Apartheid context” (Liz McGregor, ‘Interview with Phaswane Mpe’ in *Words Gone Two Soon: A Tribute to Phaswane Mpe and K. Sello Duiker*, ed. Mbulelo Vizikhungo Mzamane (Pretoria: Umgangatho Media, 2005), p. 42). Conversely, Rob Nixon notes that after the Apartheid ‘moment’, “South Africa [...] has been rediscovered as ordinary” and thus lost the interest of global readers. (Rob Nixon, ‘Non-Fiction Booms North and South: A Transatlantic Perspective’, *Safundi: The Journal of South African and American Studies*, 13 (1-2), (2012) p. 31).

Liz McGregor's *Khabzela!* (2006). Both authors situate their practice between the academy, and journalism or commercial non-fiction, and bring creative techniques to their writing in ways which ask the readers to pay attention to the authority claims of their biographical work. Through their titles, these texts present a single life as paradigmatic of the polis: I unpack the implications of this for both the narrative of HIV/AIDS and of the nation, including the fact that both present the male experience as representative, drawing on Steinberg's own re-assessment of his data one decade after the book's publication which places greater analytic emphasis on the women of 'Ithanga'. The chapter concludes with a brief discussion of Redi Thlabi's *Khwezi* (2017), which offers a rare perspective on the meaning of the HIV/AIDS epidemic through the life and death of a South African woman.

Finally, having explored the ways in which the HIV/AIDS phenomenon has been traced onto the body social of South Africa, I extend the discussion to concurrent negotiations around representation, discourse and knowledge production taking place beyond the country's borders. As a whole, the thesis builds on existing scholarship on postcolonial literature, engaging with the epistemic gaps and injustices whereby narratives from outside of the Global North are under-read, frequently mis-read or read in relation to the Western canon of literature and literary criticism. It brings these ideas together with medical humanities scholarship, and seeks to trace the intersections between biomedicine, (illness) narratives as patient empowerment, and the suppression of 'Other' cultures. Against this background of intertwining disciplinary threads, the thesis reveals ways in which HIV/AIDS as a social phenomenon in South Africa accrued a plethora of conflicting meanings that were rooted in diverse epistemic vantage points. The division produced by the Apartheid system along ethnic lines has left barriers to communal understanding, which are discussed in relation to various texts throughout the thesis. These impediments have an effect not only on our ability

to read the narratives which have responded to HIV/AIDS, but also in practical terms on the ability of decision-makers to apprehend clearly the needs of affected populations, and consequently, to effectively achieve goals of a humanitarian nature.

## CHAPTER TWO – READING THE MBEKI SCANDAL: NARRATIVE, CHARACTER AND MEMORY

The story was crying to be told... The main characters were obvious.

Kerry Cullinan and Anso Thom, *The Virus, Vegetables and Vitamins* (2009)

Blaming Mbeki has been an easy response to explain the disappointing outcome, but it is little more than a fig leaf.

David Dickinson, *A Different Kind of AIDS* (2014)<sup>150</sup>

In South Africa, what has become the ‘story’ of HIV is inextricably tied to the vicissitudes of politics and ideology that have held sway in the country - and arguably above all to one man: Thabo Mbeki. Biographers and historians chorus that they cannot tell his story without understanding his views on HIV/AIDS,<sup>151</sup> even as a definitive consensus on his opinions remains elusive. Meanwhile, as the epigraph from the health journalists and activists Kerry Cullinan and Anso Thom suggest, Mbeki is inexorably written into the local epidemiological narrative – even as the meaning of these portrayals range from architect of genocide to tragic hero, and from scapegoat to deluded crank. In one recent novel, *Tales of the Metric System* (2014) by Imraan Coovadia, he appears as a fictionalised character, clearly identifiable by his

<sup>150</sup> Kerry Cullinan and Anso Thom, *The Virus, Vegetables and Vitamins: The South African HIV/AIDS Mystery* (Johannesburg: Jacana Media, 2009), p. vii; David Dickinson, *A Different Kind of AIDS* (2014), p. xxvii.

<sup>151</sup> An exception is Adekeye Adebayo’s 2016 Jacana Pocket Biography, which lingers on the epidemic for a total of two out of 160 pages, despite concluding that “it is clear that the AIDS debacle will do the most damage to Mbeki’s presidential legacy [and be] the worst blemish on his record” (Adekeye Adebayo, *Thabo Mbeki* (Johannesburg: Jacana Media, 2016), p.105). Adebayo’s brevity on the subject seems to accord with the rest of the volume’s emphasis on Mbeki’s pan-African achievements, which he considers to have been unfairly eclipsed by the AIDS and Zimbabwe scandals.

famous nickname ‘the Chief’, who deludedly encourages his right-hand man to eschew antiretroviral medication in favour of vitamins and garlic to prove a personal point. Recent biographical accounts, on the other hand, have striven to redress the metonymic association of Mbeki with AIDS denialism by contextualising his actions within the wider political and intellectual terrain. This chapter evaluates how (and for what various purposes) the statesman Thabo Mbeki has been written into the overarching narrative of HIV/AIDS in South Africa as its protagonist, paying particular attention to how the discursive sites - including race, sexuality, the postcolonial African state, Western modernity and scientific knowledge - traversed by his biography become themes at stake in each author’s telling.

The dust has still not settled on this series of events: as Jonny Steinberg comments in a 2016 article, ‘[t]here is no uncontroversial telling of this history’.<sup>152</sup> While scholars of narrative and discourse agree that a single, objective telling of any history can only be imagined, the Mbeki/AIDS story comes to us through markedly fractured and refracted accounts. The various competing narratives in circulation are constructed from highly different epistemic starting points - which all carry an intense moral charge, are to a greater or lesser extent incompatible, and thus destined to clash. I suggest that these clashing perspectives could be very roughly accounted for in four categories: (1) South African detractors; (2) External detractors; (3) External sympathisers; and (4) South African sympathisers. The texts discussed within this chapter exist along the spectrum of epistemic vantage points that are at play here, and can be seen as implicitly or explicitly responding to all of these views. In fact, the ways in which the narratives actively respond to and contest antagonistic vantage points is revelatory of meaning-making processes in a landscape marked by epistemic injustice.

<sup>152</sup> Jonny Steinberg, ‘Re-examining the Early Years of Anti-Retroviral Treatment in South Africa: A Taste for Medicine’, *African Affairs*, (2016), 60-79, pp. 63.

Narratives falling into my first category of South African detractors draw heavily on the rhetorical palette of the liberation struggle and the 1996 Constitution, thus constructing Mbeki and his government as having betrayed the nation's democratic ideals. Predominantly concerned with South African discourse and experience, Mbeki's actions are largely set within the context of ANC history rather than that of global public health per se. These voices, which include the TAC, avail themselves of the emotionally and morally resonant language of the struggle (for example comparing AIDS to a second or 'medical Apartheid', and appropriating protest songs and chants for their marches), as well as the steelier language of the law, which was ultimately successful in forcing the ANC to provide ART through the Constitutional Court. Crucially, Mbeki's actions over AIDS are seen to shed light on the state of South Africa's political culture and to signal the beginning of the end of idealistic illusions. For example, Kerry Cullinan and Anso Thom write in the introduction to *The Virus, Vitamins and Vegetables* (2009):

The trust that many citizens once had in their democratically elected government has also been ruptured. How did Mbeki and Tshabalala-Msimang – once heroes of the anti-Apartheid revolution – and all their sycophantic supporters stray so far from acting in the best interests of ordinary people? Could they not see the suffering of the millions of their electorate through the bullet-proof, tinted windows of their official vehicles, as they died painful and lonely deaths...?<sup>153</sup>

In this framing, Mbeki betrays the ideals of the ANC by – like the oppressive regime before him – denying the basic human rights of his people to health and human flourishing. Mbeki's objections to the pharmaceutical options available are taken as evidence of his corruption by

<sup>153</sup> Kerry Cullinan and Anso Thom, *The Virus, Vegetables and Vitamins* (2009), p. x.

the new luxuries of government life that separate his lived experience from those of the people he claims to serve.

My second category of ‘foreign’ detractors meanwhile focus on what they see as Mbeki’s crimes against science, knowledge or protocol. As described in the previous chapter, most international media outlets tended to share a scathing attitude towards Mbeki’s ‘AIDS denialism’. These accounts tend to reproduce the hegemonic Eurocentric narrative, and - it is possible to infer - their scepticism that African-based expertise should have authoritative impact in the global health arena (on top of objections to statesmen interfering in scientific knowledge-making). Ironically, while both of these first two groups wanted Mbeki to submit to the international AIDS establishment’s recommendations to provide antiretroviral treatment as a first order of business, in the former category Mbeki is constructed as elitist and arrogant, caught up in futile intellectual prevarications and out-of-touch with the suffering on the ground, where commentators in this latter category are more likely to dismiss his claims in antithetical terms of scientific illiteracy, ignorance or jingoistic nativism. The American professor of comparative literature Daniel Herwitz perceives a more mercenary rationale, ascribing Mbeki’s African Renaissance philosophy to an intellectually lazy attempt to paper over the fragilities of the young state with populist rhetoric. He depicts it as an ideology designed to further the ANC’s party politics, “an absurd and horrifying attempt to concentrate state power and authority over even knowledge practices [which] can be seen in the stand President Mbeki has taken in the early months of the year 2000 on HIV/AIDS”.<sup>154</sup> Omitting reference to ways in which knowledge practices in South Africa had been warped by the Apartheid and colonial authorities, this position follows a discursive trope scripting

<sup>154</sup> Daniel Herwitz, *Race and Reconciliation: Essays from the New South Africa*, (Minneapolis: University of Minnesota Press, (2003), p. 95.



postcolonial African leaders as incapable of mastering the institutions and demands of modernity.<sup>155</sup> For these writers, Mbeki's AIDS policy represents not a volte-face from the party's accomplishments but business-as-usual in the postcolony.

More sympathetic onlookers from abroad can be seen as pushing back against or complicating the narrative produced by the second category, which they analyse as playing into under-examined power/knowledge dynamics. (This category is however complicated by also encompassing the 'AIDS dissidents' who adopted him as a proponent and even 'patron' of their challenge to medico-scientific orthodoxy, even though for those scientists the particularity of the Global Southern epistemic vantage point is minimally relevant as they would consider their views on AIDS to be, rather traditionally, universal and empirical). Narratives in this third category include academics, sociologists and anthropologists such as Paul Farmer and Didier Fassin, who aimed to contextualise Mbeki's decisions.<sup>156</sup> For example, Fassin's monograph *When Bodies Remember* states that "the AIDS controversy in South Africa invites us to revisit our idea about the role of social conditions in the productions of medical norms".<sup>157</sup> In other words, rather than seeing the debate through relativist terms as taking place in a foreign/Other social environment, Fassin and similar

<sup>155</sup> Herwitz goes on to speculate ("I am not saying that this is the government's position, I am saying I suspect it probably is") that Mbeki's policies were an effort to disguise his actual coldness towards those affected by the epidemic: "the knowledge issue, posed by the African renaissance, was in part a disguise for a more insidious, problematic agenda, a Malthusian one [...] Now if this is the choice – millions of orphaned children living degraded, suffering lives and causing social havoc, or their quicker deaths – and you choose the latter, you had better never say so in public..." (Daniel Herwitz, *Race and Reconciliation: Essays from the New South Africa* (Minneapolis: University of Minnesota Press, (2003), p. 100; p. 99)

<sup>156</sup> Hedley Twidle also sees likenesses between the arguments of Fassin and the biography of Thabo Mbeki written by the South African Mark Gevisser. "In both [books] we are shown that Mbeki is no eccentric dissident; rather 'he gives voice to an aggrieved and quintessentially African experience one shared by millions' [that] the international discussion on AIDS is yet another discourse on illness that remains 'silent about poverty, about political economy, about the modern environmental conditions that have been killing Africans for generations'" (Hedley Twidle "'In a Country where You couldn't Make this Shit up?': Literary Non-Fiction in South Africa", *Safundi: The Journal of South African and American Studies*, 13(1-2), (2012), p. 22).

<sup>157</sup> Didier Fassin, *When Bodies Remember* (2007), p. xiii.

sympathetic voices argue that the epistemic issues and practices at stake are universally relevant. While social conditions may produce different medical norms in different locations, it is naive to consider any place an exception from this process of production. In contrast to Herwitz's position, writers like Farmer and Fassin stress the role played by colonial and neo-colonial knowledge practices in producing epistemologies of distrust and doubt in nations with long experience of exploitation.

The final category, South African sympathisers, is populated with accounts by first-hand witnesses and political sounding boards of Mbeki, which have more recently emerged into the publishing marketplace (due in part to declassification of the events). As in the first category, these South African writers frequently reference the ethical and legal mandate bequeathed to them in the transition to democracy, but here Mbeki is cast as the hero rather than the antagonist. In these portrayals, he is understood to be upholding, rather than neglecting, his ethical responsibilities to his people. In his memoir *The Things That Could Not Be Said* (2013), the Reverend Frank Chikane, former Director-General to the Presidency under both Mandela and Mbeki, writes that it is his personal conviction that Mbeki saw himself as defending his citizens from "racist attitudes [...] He was not going to allow the historically disadvantaged, oppressed and exploited to be undermined and treated as less than human".<sup>158</sup> Given that the first three categories have received the most scholarly attention, I

<sup>158</sup> Frank Chikane, *The Things That Could Not Be Said* (2013), 284. The incommensurability of the two South African groups' belief can be mapped onto two different nominally emancipatory traditions. In the wake of the ideological collapse of the Soviet Union, human rights (defined along capitalist models of development) became the absolute for resistance against oppression. However, Boaventura de Sousa Santos reminds us that "for many years after the Second World War human rights were very much part and parcel of Cold War politics, and were so regarded by the Left. Double standards, complacency toward friendly dictators, the defense (sic) of tradeoffs between human rights and development – all this made human rights suspect as an emancipatory script" (Boaventura de Sousa Santos, 'Human Rights as an Emancipatory Script? Cultural and Political Conditions' in *Another Knowledge is Possible: Beyond Northern Epistemologies* ed. by Boaventura de Sousa Santos (London: Verso, 2008), p. 3). Steeped in a socialist blueprint, the ANC and Mbeki would have been among those "progressive forces [that] preferred the language of revolution and socialism to formulate an emancipatory politics" (p. 3).

devote most time in this chapter in exploring how these authors construct themselves as intervening in the prevalently known narrative, which they perceive to have been impoverished by a certain lack of transparency - in some cases borne out of necessity due to political confidentiality, and in other cases related to wilful misrepresentation of African meanings. Where they are critical of Mbeki, the decisions tend to be characterised as mistakes of a strategic or policy-based - rather than an epistemological or ethical - kind.

### **Thabo Mbeki as Historical Protagonist**

Globally, the Mbeki family name is less familiar than Mandela's, but within South Africa its political pedigree is associated not only with Thabo but also his father Govan, the eminent former ANC leader who was imprisoned on Robben Island together with Nelson Mandela, and his brother Moetletsisi, an author and political economist. Thabo Mvuyelwa Mbeki is the second of four children to Govan and Epainette Mbeki, born in what is now the Eastern Cape province in June 1942. Throughout this childhood he was sent to live with different relatives across the country, as "both Govan and Epainette believed it was best that their children should live apart from their politically active parents, who constantly faced the threat of arrest".<sup>159</sup> Thabo followed in their footsteps, joining the ANC Youth League at 14 years of age and departing South Africa six years later. During his years of exile in the UK, USSR and Zambia, Mbeki gained a reputation as the protégé of then President of the ANC Oliver Tambo, and as negotiator of the end to Apartheid, making him a clear contender for Mandela's successor and earning him the nickname of the 'Crown Prince' of the ANC. Since his premature ousting by Jacob Zuma in 2008, he has remained a high-profile figure within

<sup>159</sup> Adekeye Adebajo, *Thabo Mbeki* (2016), p.30.

the South African political landscape, and an active statesman on the continent more widely. In 2016, he was appointed the Vice-Chancellor of the University of South Africa (UNISA), in which role he continues the promotion of his African Renaissance philosophy.

Often characterised in terms of his reserve and introversion, Mbeki was aware that he would be unable to reproduce the fascination of the larger-than-life Mandela - as few world leaders in history could. In addition to being adopted as uTata (Father) to the South African nation, Mandela has arguably been received as a protagonist of the world's collective historical consciousness - "the very personification of an icon"<sup>160</sup> - embodying to the outside world his and Archbishop Desmond Tutu's idealised vision of a peacefully reconciled, post-racial nation. The bloodshed-free transition that he oversaw, averting real fears of outright civil war in the country, seemed miraculous to many, and his characterisation as a 'terrorist' by the American and British governments was quickly swept under the rug of political amnesia (even though Mandela and other ANC leaders were officially kept on the US terrorism watchlist until 2008). Together with Mahatma Gandhi and Martin Luther King, his legacy has outgrown the particularities of his struggle and come to figure as a global symbol of harmonious racial reconciliation.<sup>161</sup>

One biographer, Adekeye Adebajo, notes that due to the inevitability of operating under Mandela's shadow, Mbeki preferred actively to eschew 'personality-cult' style leadership, to

<sup>160</sup> Lucky Mathebe, *Mandela and Mbeki: The Hero and the Outsider* (Pretoria: UNISA Press, 2012), p. x.

<sup>161</sup> Related to the beatified, ideologically neutralised status of Nelson Mandela, MLK and Gandhi are more negative sub-narratives along other axes of intersectionality. Mandela and MLK have been described as moderate and overly compromising, leading to peace on terms that benefitted the oppressor, while Gandhi has been seriously denounced for his anti-black racist beliefs. Although not without legitimacy, the gravity of these disenchantments is derived from their historically pivotal roles and the symbolic pedestals on which these figures are placed. There is little interest, by contrast, in revealing controversies from Mbeki's personal life and marriage, perhaps because his status as a political figure is so open to attack.

the extent that he avoided having a public profile altogether and granted only rare interviews. This reserve also reflects a life spent in exile from family and home, during which years ANC comrades “were living on edge all the time knowing that [they] were being watched by the security forces”.<sup>162</sup> Another biographer, Mark Gevisser, contends that the two Presidents’ contrasting attitudes towards their own life narrativisation is relevant: “[u]nlike Mandela, who made a fetish of his biography for South Africans to identify with ... Mbeki denied any relationship between his life story and the work he did”,<sup>163</sup> even though a common refrain of biographical accounts is that Mbeki’s entire life *was* the ANC and his work. If the title of Mandela’s autobiography, *Long Walk to Freedom*, relates to the story of South Africa as a nation, the Thabo Mbeki Foundation commissioned volume *The Thabo Mbeki I Know* reinforces the image of a man whose authentic self is concealed from all but a few. Where Mandela’s life is an open book, Mbeki’s is an enigma.<sup>164</sup> As a consequence of his consciously inscrutable profile, Mbeki’s personality has been ripe for interpretation:

He was a ‘bourgeois’ type, so the argument ran, and thus revealed the character that he actually was: a ‘Machiavellian Prince’ [...] The ‘Machiavellian story of Thabo Mbeki, which, since 1994, was constantly invoked to explain the essential difference between his style and that of Mandela, descended for all time into a negative point, a point that defined Mbeki as he would not define himself.<sup>165</sup>

<sup>162</sup> Tiksie Mabizela, ‘Tiksie Mabizela’ in *The Thabo Mbeki I Know* ed. Sifiso Mxolisi Ndlovu and Miranda Strydom (Johannesburg: Picador 2016), p. 25.

<sup>163</sup> Mark Gevisser, *Thabo Mbeki: The Dream Deferred*, xxii.

<sup>164</sup> In his prequel to *The Things That Could Not Be Said* which describes the events at Polokwane in 2008, Frank Chikane writes “Initially I had planned chapters with titles like ‘Understanding the real Mbeki!’, ‘Mbeki: What is Enigmatic about him?’, ‘Mbeki and the Media’ [...] Unlike many politicians, Mbeki did not believe in premeditated media exposure or branding. At the beginning, a number of companies offered to assist him with branding and building his image and his response was a categorical no” (Frank Chikane, *Eight Days in September: The Removal of Thabo Mbeki* (Picador Africa 2013), Kindle Locations 3775-3776).

<sup>165</sup> Lucky Mathebe, *Mandela and Mbeki* (2012), p. x.

Biographers have noted that Mbeki is celebrated more in a pan-African context than on the world stage or indeed within his own country. He is known in this framework for his African Renaissance vision, which encompassed foreign policy achievements such as his architecting of the New Partnership for Africa's Development (NEPAD) in 2001, involvement in the launch of the African Union (AU) in 2002, and peace-making in the Democratic Republic of Congo, Zimbabwe, Cote d'Ivoire and other countries. In evoked comparisons with *uhuru* leaders such as Kwame Nkrumah, and in accolades as "the foremost international stalwart and statesman of his generation in Africa",<sup>166</sup> he fares rather better than in contrast with Mandela.<sup>167</sup> As Mandela's Deputy President, Mbeki also contributed to the symbolic reconciliation of South Africans with his famous 'I am an African' speech, which was delivered on the occasion of the passing of the new Constitution in May 1996 and which envisaged a hybrid, already globalised identity that could encompass the multiple racial categories of South Africa without inconsistency. I reproduce a small part of the speech here:

I am formed of the migrants who left Europe to find a new home on our native land.

Whatever their own actions, they remain a part of me [...] I am the grandchild who lays fresh flowers on the Boer graves at St Helena and the Bahamas, who sees in the mind's eye and suffers the suffering of the simple peasant folk, death, concentration camps [...] I am the child of Nongqawuse.<sup>168</sup> I am he who made it possible to trade in the world markets in diamonds,

<sup>166</sup> Barney Afako, 'Foreword' in *The Thabo Mbeki I Know*, ed. Sifiso Mxolisi Ndlovu and Miranda Strydom (Johannesburg: Picador, 2016), p. xiv.

<sup>167</sup> Mbeki's focus on pan-African unity and development, including his involvement in Zimbabwe (which led to his spending almost the whole of 2008 outside of South Africa) was less warmly embraced by his citizens. The post-Apartheid authorisation of free movement within the SADC region led to heavy immigration into South Africa from neighbouring countries, and prejudices against newcomers and refugees have been a source of enormous social conflict, culminating in severe outbreaks of xenophobic violence in 2008 and 2015. Immigrants and refugees have unsurprisingly also been scapegoated for bringing and/or spreading HIV/AIDS.

<sup>168</sup> Nongqawuse was a fifteen-year-old Xhosa girl who received a vision in April 1856 that the Xhosa nation should destroy their crops and cattle (which were dying from a lung disease imported along with British herds) in order to defeat the British armies. She claimed that the spirits had told her that if these instructions were followed, miracles would occur including that the aggressor forces would be swept into the sea. The cattle-killing by believers led to a famine in what is now the Eastern Cape. These events were chronicled in historian

gold, in the same food for which my stomach yearns. I come from those who were transported from India and China, whose being resided in the fact, solely, that they were able to provide physical labour [...] Being part of all these people and in the knowledge that none dare contest that assertion, I shall claim that – I am an African.<sup>169</sup>

Within South Africa, however, his emphasis on uplifting a pan-African identity was sometimes critiqued as ‘nativism’ or neglect of his own country’s issues, while his economic compromises led to disaffection from those who had been oppressed under Apartheid: “Eventually, his critics on the left and the right came together in a single chorus [...] those on the left claimed he had embraced reconciliation in the absence of justice, and those on the right accused him of turning to the question of justice for demagogic reasons [...] so as to turn the demand for justice into a racial vendetta<sup>170</sup>. The HIV/AIDS issue can be seen to traverse all of these various discursive sites, from disputes over correct allocation of finances and Mbeki’s prioritisation of African interests to rhetoric about AIDS as a ‘second Apartheid’ (which imply that the original state of Apartheid dissolved with Mandela’s election). Mbeki’s own international reputation as a President became inexorably intertwined with his policies that most contradicted those of the West: his ‘AIDS denialism’ and his ‘quiet diplomacy’ approach to Robert Mugabe’s land reforms in Zimbabwe.

Jeffrey B. Peires’ *The Dead Will Arise: Nongqawuse and the Great Xhosa Cattle-Killing of 1856-7* (Johannesburg: Jonathan Ball 2003).

<sup>169</sup> BBC, ‘Thabo Mbeki’s speech: full text’ (1999) < <http://news.bbc.co.uk/1/hi/world/africa/370679.stm> > [Accessed 8th September 2018].

Where Mandela and Tutu embodied the spirit of ‘Reconciliation’, Mbeki is arguably more driven by the compulsion to ‘Truth’ (or rather, he was more unwilling to subsume the former to the latter) Thus, his picture of a Rainbow Nation made up of the descendants of indigenous African, settler Dutch, and indentured Indian and Chinese people foregrounds their economic and historic inter-dependency (with its references to the ‘peasant folk’, ‘world markets’ and ‘physical labour’) as much as their shared humanity: it is a Marxist rather than a Christian line of emancipation. His foregrounding of the need for repair through unlearning and rescripting is already clear in this speech

<sup>170</sup> Mahmood Mamdani, *The Thabo Mbeki I Know*, ed. Sifiso Mxolisi Ndlovu and Miranda Strydom (Johannesburg: Picador 2016), p. xx.

In an interesting contemporaneous juxtaposition to the surge in illness narratives that AIDS produced in the United States, Rob Nixon attributes the fall in global reading public interest in works from South Africa to Mbeki's ascension to power. The country had - during the years of struggle against Apartheid crimes and triumphant advent of multiracial democracy in 1994 - captivated the world with accounts by liberal writers such as J.M. Coetzee and Nadine Gordimer and then by what Nixon calls the two literary "Oprah arc"<sup>171</sup> moments: Mandela's auto-biography, *Long Walk to Freedom*, published in 1994, and the Truth and Reconciliation Commission of 1996. However, Nixon writes:

A third, potentially exceptional moment came and went: Mbeki's surreal, scandalous HIV/AIDS denialism. While this got some (largely bewildered) coverage in the US, the story wasn't mediated through any defining literary work, fictional or non-fictional. [...] Indeed one might argue that within the superpower parochialism that defines the US literary scene the incomprehensibility that accrued to Mbeki's policies may have hastened South Africa's slide towards just one more strange foreign place, another unredemptive, unengaging elsewhere.<sup>172</sup>

Nixon's analysis is revealing of how South Africa's epistemic standing has shifted with its place in the geopolitical sphere, conveyed through publishing statistics. Within South Africa, naturally enough, Mbeki has a high profile. The immediate period after Mbeki's step down from power produced a number of biographies processing his tenure, while a recent spate of publications about Mbeki seems to speak to a new national moment. During the 2010s, both Zuma's governance and Mandela's irreproachability have been increasingly challenged in mainstream South African political discourse. This perhaps contributed to a revival of interest

<sup>171</sup> Rob Nixon, 'Non-Fiction Booms, North and South: A Transatlantic Perspective', *Safundi: The Journal of South African and American Studies*, 13 (1-2), (2012), p. 32.

<sup>172</sup> *Ibid*, p. 32.



in the President who provided a foil to both; in a 2011 *Sunday Times* article titled ‘Once disgraced Mbeki era now seems like the golden age’, the former opposition leader wrote that “the previous president who left office in humiliation and without much public sympathy is now viewed with fond nostalgia”.<sup>173</sup>

This second wave of biographical publications displays an interest in reassessing or rehabilitating the former President’s reign and legacy. Mbeki’s Thabo Mbeki Foundation is the engine behind *The Thabo Mbeki I Know* (2016), a hefty collection of first-person accounts by a range of close and professional acquaintances compiled by Sifiso Mxolisi Ndlovu, a historian and academic, and Miranda Strydom, former journalist and current trustee of the Thabo Mbeki Foundation. Prior to this, contributor Rev. Frank Chikane, who served as Deputy General to the President’s office under Mandela, Mbeki and Zuma, authored two political memoirs recounting first the events at Polokwane *Eight Days in September: The Removal of Thabo Mbeki* (2012) and a follow-up *The Things That Could Not Be Said: From A[ids] to Z[imbabwe]* (2013). Finally, a new Jacana Pocket Biography *Thabo Mbeki* (2016) by Professor Adekeye Adebajo, Executive Director of the Centre for Conflict Resolution in Cape Town, adds to an apparent trend of ongoing fascination with the former President and his legacy.<sup>174</sup> The following sub-section examines these contemporary ‘re-tellings’ of the controversial years between 2000 and 2003, with an end to showing how the

<sup>173</sup> Tony Leon, ‘Once disgraced Mbeki era now seems like the golden age’ <<https://www.timeslive.co.za/ideas/2017-11-01-once-disgraced-mbeki-era-now-seems-like-the-golden-age/>> [Accessed 28<sup>th</sup> August 2018]

<sup>174</sup> By contrast, during Zuma’s reign, journalist Lynsey Chutel noted that, “[w]orks about Zuma himself aren’t as likely to sell as books making sense of Zuma’s South Africa and the country he will leave behind” (Lynsey Chutel, ‘South Africa’s bestselling books are mostly about South Africa’s political dysfunction’ (2016), <<https://qz.com/africa/874444/south-africas-bestselling-books-are-mostly-about-south-africas-political-dysfunction/>> [Accessed 1<sup>st</sup> September 2018]. In fact, while still in power, Zuma’s colourful personality seemed to resist narrating, in that details appeared to provoke pessimism about the state of the country.

narrative processing of Mbeki's role in the social phenomenon on HIV/AIDS in South Africa forms a mirror onto the state of the nation.

Many of the authors discussed appear motivated to intercede in the developing archive of South African and AIDS history, attempting to fix meaning in this case to the figure of Thabo Mbeki. This aligns with theoretical understandings of narrative as attempts to communicate social reality and as a critical intervention into its meaning. There is moreover a theme of witnessing and testimony, which reinforces the 'story' of two opposing sides: the ANC versus the people. Accordingly, narratives beget counter-narratives; for example, in the introduction to the collection of essays *The Virus, Vitamins and Vegetables* (2009), the editors recorded that:

Mbeki's official biographer, Ronald Suresh Roberts,<sup>175</sup> provided the final spur for this book. When he started to promote his thesis of the 'poor misunderstood President', claiming that Mbeki had never been an AIDS dissident, we looked at each other in disbelief. History was being whitewashed before us [...] It gave us the impetus to document HIV/AIDS in the Mbeki/Manto era.<sup>176</sup>

The writings of Thom and Cullinan, and Coovadia are underpinned by the impulse of prosecution, while Roberts and Chikane are among those who take up the defence on his behalf. The influence of the Truth and Reconciliation legalistic framework can perhaps be recognised in the interaction between these texts. Discussing South African literature in the aftermath of the TRC, Shane Graham argues that "characteristic features of post-TRC literature [include] narrative forms such as confession and second-person direct address" and

<sup>175</sup> Roberts' book itself demonstrates a desire to counter prevalent narratives with its subtitle, *Fit to Govern* (2006).

<sup>176</sup> Kerry Cullinan and Anso Thom, *The Virus, Vitamins and Vegetables* (2009), p. xi.

that these techniques “teach us to be suspicious of fixed, immutable narratives of historical truth, and to query the motives and interests of those who most insistently proffer their narratives”.<sup>177</sup>

Finally, although Mbeki is yet to publish an autobiography or memoir (if indeed he ever intends to do so), Mark Gevisser’s reading of his subject suggests that Mbeki’s own sense of himself as a protagonist – specifically, a tragic protagonist - may be key to understanding the events of the early 2000s. “Thabo Mbeki”, he writes, sees himself as “a prophet-in-the-wilderness”,<sup>178</sup> one whose intellect and strategic foresight led him to challenge the ANC to embrace the free market and the Euro-American powers as the Soviet Union, their former ideological ally and source of financial backing, collapsed in the previous decade.

Now, in the era of the dream deferred, in the difficult transition, he found himself once more in a tiny minority of free-thinking dissidents. Once more, he might be overwhelmed by conventional thinking. But once more, in the long run – he believes, with absolute conviction – he will be proven correct.<sup>179</sup>

In the conventions of literary tragedy, the hero’s downfall is produced through his tragic flaw or *hamartia*: an incommensurability between his/her fundamental values and those of society. Gevisser has memorably identified Mbeki with Coriolanus, the protagonist of one of Mbeki’s favourite Shakespeare plays,<sup>180</sup> a tragedy about the vacillation of public opinion. Principled

<sup>177</sup> Shane Graham, *South African Literature after the Truth Commission: Mapping Loss*, (Hampshire: Palgrave Macmillan, 2009), p. 5.

<sup>178</sup> Mark Gevisser, *Thabo Mbeki* (2007), p. 735.

<sup>179</sup> Ibid, p. 735.

<sup>180</sup> Gevisser recalls being struck when Mbeki relayed to him a Marxist theorist’s interpretation of Shakespeare’s tragic heroes which he appreciated, that “the person who does good, and does it honestly, must expect to be overpowered by forces of evil... But it would be incorrect not to do good just because death is coming” (2007: xl).

but to the point of uncompromising rigidity, Coriolanus refuses to pander to the citizens by playing the necessary political games and is ultimately banished from Rome for his seeming arrogance and contempt for the citizens. In one way, the comparison is elevating: Mbeki's obstinacy is cast as purity of vision, so that he appears as another in a line of African uhuru (freedom) leaders who were prematurely removed from the seat of power,<sup>181</sup> and his questioning of international AIDS doctrine becomes "nothing more than a continuation of the quest to which Mbeki had dedicated his whole life: that of [African] self-determination and self-definition".<sup>182</sup> It is easy to understand how Gevisser sees Coriolanus' traits and flaws in the man who rejected political image-making to the extent that he "shunned a public profile almost entirely"<sup>183</sup> and refused to take a HIV test in public because it "might be dramatic and make newspaper headlines [but] would be irrelevant" to his own perception of the issue.<sup>184</sup>

On the other hand, the clash in which Coriolanus is caught up is one between the patricians and the common people. The latter find that Coriolanus looks down upon them and, at bottom, is contemptuous of the problems they live on a daily basis – and there is resonance to this also.<sup>185</sup> Most difficult to understand is Mbeki's self-righteous failure publicly to express his compassion for the lives that were lost to AIDS during his administration, which could

<sup>181</sup>

<sup>182</sup> Mark Gevisser, *Thabo Mbeki* (2007), p. 744. Chikane corroborates the alignment of Mbeki with a tragic heroic convention, writing that "he was so committed to the cause of combating racist attitudes – even in dealing with health issues – that he was ready to die for it, both politically and personally. (Frank Chikane, *The Things That Could Not Be Said* (2013), p. 284.)

<sup>183</sup> Mark Gevisser, *Thabo Mbeki* (2007), p. xxii.

<sup>184</sup> Ibid, p. 727.

<sup>185</sup> In her contribution to *The Thabo Mbeki I Know*, former chairperson of the Independent Electoral Commission Brigalia Bam recalls that "some of us caucused around him and how we could try and change his serious image [...] we thought he should try and hold and kiss babies and rehearse all those other things that go along with being a president in the public sphere" (Brigalia Bam, 'Brigalia Bam' in *The Thabo Mbeki I Know*, ed. by Sifiso Mxolisi Ndlovu and Miranda Strydom (Johannesburg: Picador, 2016), p. 15. However, this plan was quickly abandoned: "I just could not and would not have dared to try. I just think some people are like that" (2016, p. 15).

have been done without assuming total responsibility for those deaths or backtracking on his policies or beliefs. Cullinan and Thom's question, "Could they not see the suffering of the millions of their electorate...?" thus remains unanswered. As a tragedy, however, Coriolanus' fate is designed to be revelatory both of the social and political culture of Rome and of his character. The points upon which Mbeki proved so immovable similarly can best be understood in the context of the particular socio-economic, geopolitical and epistemic situation which he navigated as President.

### **Searching for a Scapegoat**

While the texts discussed in this chapter share a topical concern with HIV/AIDS, they do not take the perspective of the 'patient' or 'sufferer' or physician: they in fact do not approach the epidemic with a strictly medical gaze. As such, they do not correspond to the traditional picture of an 'illness narrative', even though Neil Vickers has described this category as an incredibly "capacious" one, that can contain almost any kind of text in which "illness plays a conspicuous part".<sup>186</sup> I propose that these writings can be more accurately apprehended under the proposed term 'disease narratives', in that their mutual intention is to make sense of the epidemic at the level of the social rather than individual body. If illness provides "an occasion for stories" about the self and its limits,<sup>187</sup> then a disease that becomes endemic to a nation might equally prompt narratives to repair the damage it inflicts, to take stock, and to reinscribe a map and destination. To extend the metaphors of shipwreck and navigation that I derive from Frank's *The Wounded Storyteller*, President Mbeki found himself Captain of the

<sup>186</sup> Neil Vickers, 'Illness Narratives' in *A History of English Autobiography*, ed. by Adam Smyth (Cambridge: Cambridge University Press 2016), p. 388.

<sup>187</sup> Arthur Frank, *The Wounded Storyteller* (2013), p. 53.

new South Africa's maiden voyage as AIDS struck. Cast as the protagonist of the story of AIDS in South Africa, Mbeki thus appears in another metaphorical sense as the diseased part of the social body, whose neutralisation had to occur before healing could begin.

In Frank's typology of illness narratives, the 'chaos narrative' of overwhelming fear and anxiety which illness often provokes has a tamed mirror-image in the 'restitution narrative', which says 'Yesterday I was healthy, today I'm sick, and tomorrow' I'll be healthy again', and which is made possible and promoted by modern high-tech medicine.<sup>188</sup> If we can extend Frank's analysis of personal ideotypes of distress and story-telling to the level of the body social, in order to probe the usefulness of the 'disease narrative', we could argue that when HIV/AIDS struck, South Africa was, as a whole, affected by these divergent possibilities of 'chaos' and 'restitution'. Given that effective management of HIV involves a lifetime on ARVs, whether the epidemic is experienced as a chaotic or a restorable event is deeply contingent on access to this medication. This zero-sum understanding of the conflict offers some insight into the impasse that ensued, as the ANC's refusal to allow this technology into the market therefore prolonged the state of chaos - which Frank tells us is experienced as unbearable anxiety - on a national level. Once ART became widely available in the West, the production of AIDS illness narratives became noticeably less prolific and they attracted far less attention, which speaks to those narratives' purpose: to confront mortality, to bear witness and to deal with feelings of helplessness in the face of psychological chaos.

Commentators often note that one of the greatest shocks that HIV/AIDS made to the world was the disillusionment in the theretofore triumphant, teleological narrative of medical

<sup>188</sup> Neil Vickers, 'Illness Narratives', in *A History of English Autobiography*, ed. by A Smyth (Cambridge: Cambridge University Press, 2016), p. 10.

progress, which had seemed confirmed by a series of breakthroughs like the eradication of smallpox in 1980. However, “[a]fter AIDS, the doctor was no longer God [...] This was the profound legacy of the epidemic in the West”.<sup>189</sup> Jean Comaroff has located the impact of the epidemic partially in the way that it surpassed “the received limits of virology and immunology – indeed, of the restricted lexicon of bioscience *sui generis*”, an unexpected event that set off “an avalanche of mythmaking”.<sup>190</sup> Deprived of science’s certitude, the need for resolution can be seen in some ways to be displaced onto the ‘character’ of Mbeki, a single individual around which narratives can more easily be made to coalesce, and who moreover seemed to cast himself in the antagonist role by personally challenging the hegemonic power of the international scientific community. Reading the colossal issue of HIV/AIDS in South Africa – an issue that on closer examination proves to have unwieldy roots spanning continents and centuries – through one [Deputy] President gives the epidemic a manageable, human scale, so that the abstract, multi-disciplinary debates can be boiled down to the binary question: Does Mbeki believe HIV causes AIDS, yes or no?

As previously outlined, after Mbeki agreed to the NEC’s request that he would take a step back from allowing his personal opinions to determine national HIV/AIDS policy, South Africa has pivoted from being the despair of the international AIDS community to managing what is now the largest ARV programme in the world.<sup>191</sup> Inarguably, Mbeki and his government ministers’ prevarication presented an enormous and deplorable obstacle to the treatment and care of PLWHA in South Africa. This study in no way wishes to refute this fact. Nevertheless, David Dickinson maintains that while the “folksy portrayal” of “an ‘AIDS

<sup>189</sup> Mark Gevisser, *Thabo Mbeki: The Dream Deferred*, pp. 751.

<sup>190</sup> Jean Comaroff and John Comaroff, *Theory from the South* (2012), p. 174.

<sup>191</sup> This achievement, it should be noted, built on the groundwork created by the joint victory of civil society and government in passing the Medicines and Related Substances Control Act (1997).

community' [made up of] a principled band of campaigners, armed with truth and reason up against a small cast of deluded but powerful miscreants"<sup>192</sup> surely has all the ingredients of a stirring narrative, it may remain to a surprising extent irrelevant to segments of the population most vulnerable to HIV infection who do not share either side's worldview. Relatedly, while the introduction of 'Drugs into Bodies' appeared to level the lot of PLWHA in the Global North and South, it did not remove entrenched problems like the ongoing inequity of health services within South Africa and globally; or the problematic power relations between global health bodies and non-governmental organisations and the disempowered poor; or the historical crimes of medicine and its related barriers in certain communities; all of which are problems that contributed to HIV/AIDS spreading in South Africa before its existence was medically detected, and that continue to beset public health programmes in both the HIV/AIDS context and in other public health contexts. It also does not address why South Africa has such a high incidence of HIV/AIDS in the first place. As Dickinson points out, even a decade after Mbeki's withdrawal from the policy field and the replacement of Tshabalala-Msimang as Health Minister, alternative paradigms of HIV epidemiology remain in wide circulation in parts of the country. If people understand the disease in non-allopathic terms, standard prevention and treatment services – even when available and accessible - may not register as legitimate options within their field of health-seeking agency. This verdict challenges a drawing of a linear correlation between Mbeki and the incidence and prevalence rates of HIV/AIDS in South Africa, and thus demands that we read the story in greater depth.

One singular aspect of HIV/AIDS in all contexts has been the heightened ways in which it was politicised, implying that it was imbued with greater human culpability and motivation

<sup>192</sup> David Dickinson, *A Different Kind of AIDS* (2014), p. 289.



than other diseases. The anthropologist Didier Fassin informs us that, “[e]pidemics are moments of truth when both knowledge and power are put to the test. Doctors test their theories, and citizens expect concrete results from the authorities”.<sup>193</sup> At the same time, however, they are moments of severe destabilisation of those relationships between truth, knowledge and power. In 1990, the medical sociologist Philip Strong proposed that epidemics and other comparably dramatic social crises produce a particular model of ‘epidemic psychology’, which manifests in three subcategories: epidemics of fear, epidemics of interpretation or moralisation, and epidemics of action or proposed action. According to Strong, “one striking feature of the early days of such epidemics seems to be a strikingly volatile intellectual state [leading to] a collective disorientation”.<sup>194</sup> He sees the psychological responses of fear, interpretation and calls for action as themselves contagiously ‘epidemic’, because they have the capacity to affect (separately from the disease itself) almost anyone in the population: “everyone has the capacity to decide that something must be done and done urgently”.<sup>195</sup> While most diseases remain within the remit of specialists, an epidemic such as HIV/AIDS can therefore sweep through all sectors of society, with a wide range of non-medically trained people seeking to define its meaning, moral or solution.

As introduced in the previous chapter, some interpretations are able to gain more traction than others, due to their proximity to hegemonic narratives or their place in hierarchies of knowledge production. In the case of HIV/AIDS, international bodies headquartered in the Global North such as UNAIDS, the WHO, PEPFAR and the Global Fund – in tandem with pharmaceutical corporate giants - entrenched the crucial biomedical account, which

<sup>193</sup> Didier Fassin, *When Bodies Remember* (2007), p. 32.

<sup>194</sup> Philip Strong, ‘Epidemic Psychology: a model’ (1990), p. 254.

<sup>195</sup> *Ibid.*, p. 251.

privileged experiences of minorities within the Global North environments, and were then fed into the official interpretations and action plans around prevention, treatment and care. In the case of South Africa, where there was an experientially lower level of faith in the benevolence of hegemonic narratives, Fassin contends that the dissident theorists' *lack* of proximity to hegemonic narratives actually improved their traction:

to borrow Dan Sperber's (1985) metaphor [we should] ask ourselves why certain representations are more contagious than others... If responsible politicians, beginning with the head of state, are so taken with the heterodox model, it is because, even before they have ever heard of it, it reflected their own preoccupations.<sup>196</sup>

The intersection between existing epistemic injustices and epidemic psychology is pertinent to understanding the conflicts and controversies that emerged in South Africa around HIV/AIDS. Strong argues that "[w]hen routine social responses are unavailable, then a swarm of different theories and strategies may compete for attention".<sup>197</sup> Mbeki gave undue credence to a range of these different theories and strategies, particularly a group of 'AIDS dissidents' including the Berkeley academic Peter Duesberg, whose arguments about this disease had already been rejected by the scientific community for some years.<sup>198</sup> At his opening speech to the 2000 International AIDS Conference, he objected that his efforts to consider different perspectives had brought disproportionate censure on him and his government:

<sup>196</sup> Didier Fassin, *When Bodies Remember* (2007), p. 57-61.

<sup>197</sup> Philip Strong, 'Epidemic Psychology' (1990), p. 253. In retrospect it seems that Mbeki and the dissident view formed a binary opposition to a unified, mainstream consensus on HIV/AIDS and its treatment and epidemiological model. However, as chronicled in journalist Bruce Nussbaum's 1990 book *Good Intentions*, the process of drug development was far messier and dependent on politics and chance.

<sup>198</sup> For example, M.S. Ascher et al, 'Does drug use cause AIDS?', *Nature* 362(6416), (1993), 103-4. Duesberg claims that the HIV virus itself is harmless and remains the most prominent proponent of heterodox explanations for the epidemic.

Some in our common world consider the questions I and the rest of our government have raised around the HIV/AIDS issue, the subject of the Conference you are attending, as akin to grave criminal and genocidal misconduct.

What I hear being said repeatedly, stridently, angrily, is – do not ask any questions!<sup>199</sup>

Mbeki may not have been asking the correct questions, or the correct people, at all times, but his objection that he was not permitted to ask questions at all is worth taking seriously in relation to issues of epistemic inequality, particularly given the disproportionate tolerance for substandard practice in medical knowledge production and practice in marginalised economies.<sup>200</sup> In Chapter Two, I outlined the roots of activists' invocation of the terminology of genocide and war crime that Mbeki responded to in his speech; these emotion-laden charges increased his distrust of the hegemonic discourse and its motives.<sup>201</sup> (Strong also notes that the competing control strategies that emerge in times of epidemic may be directed at controlling the spread of the disease, but they may also aim to control "further epidemics of fear and social dissolution".<sup>202</sup>) In other dimensions, including the economy, Mbeki has

<sup>199</sup> Thabo Mbeki, 'Speech by Thabo Mbeki at the Thirteenth International AIDS Conference, July 9, 2000', in *Africa and the West: a Documentary History: Volume 2: From Colonialism to Independence* ed. by William H. Worger, Nancy L. Clark and Edward A. Alpers (Oxford: Oxford University Press), p. 234.

<sup>200</sup> In 2017, the WHO published a report revealing that one in ten medical products in developing countries are either substandard or completely falsified. In sub-Saharan Africa alone, the London School of Hygiene and Tropical Medicine estimates that an additional 116,000 deaths per year are caused by inauthentic malaria medication, with a cost of about \$38.5 million to patients and health ministries, and contributing to an additional risk of accelerating resistant disease strains (WHO, 2017).

<sup>201</sup> Mbeki's offence at being accused of genocide is also unsurprising given the recent history of South Africa and the region more widely. While the activists in the United States' were able to draw on imagery of World War Two that resonated with a wide public, the German/Nazi genocide against Herero and Nama people in Namibia, known under colonialism as German South West Africa, in which it is thought that 75% of the Herero population and 50% of the Nama population were killed, remains relatively unknown in the West. Skulls of the victims were sent to Germany, where many still remain, for eugenics research that predated and paved the way for the experiments which took place in the concentration camps. (See Jan-Bart Gerwald, 'Imperial Germany and the Herero of Southern Africa: Genocide and the Quest for Recompense' in *Genocide, War Crimes and the West: History and Complicity* ed. Adam Jones (London: Zed Books 2004); Norimitsu Onishi, 'Germany Grapples With Its African Genocide' <https://www.nytimes.com/2016/12/29/world/africa/germany-genocide-namibia-holocaust.html> [Accessed 7th September 2018]).

<sup>202</sup> Philip Strong, 'Epidemic Psychology' (1990), p. 251.

been seen to be a moderate influence within the ANC, capable of shifting deeply held beliefs in response to geopolitical realities. Arguably the epistemic authoritarianism and paternalism with which Global South countries were treated, during a time in which interpretations and evidence were still plural and yet to be wholly established, deepened the intransigence of Mbeki's position.

Jeremy Youde has stated that "if one looks at the actual text of Mbeki's speeches and writing on AIDS, it becomes clear that part of his aim is to reorient how the international community views AIDS".<sup>203</sup> In spite of his aims and the content of his communication, however, "Mbeki's AIDS policies are not *perceived* by the international community as part of a larger worldview. Mbeki may want to draw attention to global inequality, but the international community *understands* his government's policies as failures that ignore the suffering of the five million HIV positive South African adults".<sup>204</sup> There is therefore a crucial gap in the collective interpretative resources that puts Mbeki at a disadvantage in having his expression treated as unintelligible. As such, we can see Mbeki as a subject of testimonial injustice, in the deflated credibility owing to "identity prejudice on the hearer's part",<sup>205</sup> which he received as an African government leader attempting to speak about the problems faced by his country. Mbeki saw associated with the calamity of HIV/AIDS the threat of medicolonial ideologies encroaching through a human rights Trojan horse, and he was partly seeking to control the undermining of African agency, intellectual capacity and self-determination. We see the attempt to delegitimise Mbeki's concerns more clearly through the ways his handicap in epistemic authority has been reframed as one of intellectual incapacity:

<sup>203</sup> Jeremy Youde, 'Ideology's role in AIDS policies' (2007), p. 11.

<sup>204</sup> Ibid, p. 12.

<sup>205</sup> Miranda Fricker, *Epistemic Injustice* (2007), p. 4.

Accusing Mbeki of practicing “voodoo science” relegates the black man once again to the position of an ignorant tribesman steeped in magical traditions and paints the West as the bearer of rationality and enlightenment: “true science”.<sup>206</sup>

Didier Fassin has written that the “extreme personalization” of the concentration of public criticism on Mbeki and his health ministers was understandable, as part of an ultimately successful strategy in the campaign for treatment access.<sup>207</sup> However, he observes that explanations of the ANC’s dissident policies through the evocation of “irrationality, paranoia and cynicism [...] using respectively cognitive, psychopathological and political frames”<sup>208</sup> drew on narrative constructs which also played on black South African epistemic disenfranchisement in ways ultimately counterproductive to the humanitarian goals of those who wanted to curb the epidemic and support PLWHA worldwide.

As outlined in the previous chapter, the antagonism between Mbeki and the international community had been in the first place an economic one. The later epistemic issues were undoubtedly shaped by those original quarrels over generic drug manufacture and import. Western powers’ protectiveness over the pharmaceutical industries’ bottom line, and hindrance to South Africa’s efforts to lower medication prices decreased trust between the two regions. The ANC’s case against the pharmaceutical corporations was more easily recognised as an issue of unfair resource distribution and was rallied to by activists both in South Africa and worldwide. The relatively fledgling government, with the recent moral victory against Apartheid on their side, facing up to a monopolizing industry presented a

<sup>206</sup> Giuliana Lund, ‘Healing the Nation’ (2003), p. 114.

<sup>207</sup> Didier Fassin, ‘A case for critical ethnography: Rethinking the early years of the AIDS epidemic in South Africa’, *Social Science and Medicine*, (2013), 119-126, p. 123.

<sup>208</sup> *Ibid*, 122.

classic David vs Goliath narrative. As the disagreement turned from a (more purely) economic one to an epistemic one, however, Mbeki began to lose support. Fricker writes that we are still unaccustomed to “ideas such as that epistemic trust might have an irrepressible connection with social power, or that social disadvantage can produce unjust epistemic disadvantage”.<sup>209</sup>

### **‘The Chief’: Contemporary portrayals in fiction and non-fiction**

We have suggested that Thabo Mbeki presents himself to the world – intentionally - as a closed book. This opacity is acknowledged by two recent memoirs *The Thabo Mbeki I Know* (2016) and *The Things That Could Not Be Said* (2013), whose titles imply a corrective role and establish the authors or contributors as uniquely placed to reveal the unknown and the unspoken. For example, in the introduction to the former, editor Barney Afako promotes one account as “probably the most intimate portrayal of Mbeki in a domestic setting”.<sup>210</sup> Although both of these volumes are produced within the generic traditions of biography or memoir and accordingly invoke claims to certain notions of factuality or transcribed ‘truth’, they also aim to sympathetically reorient Mbeki’s image and legacy, through their stated engagement with prevailing narratives. In contrast to these biographical volumes, a recent fictional work by the Indian South African novelist Imraan Coovadia has dramatised Mbeki’s thoughts on HIV/AIDS, through an imagined and comparatively damning portrayal of the President visiting his HIV positive spokesman in hospital. As an artist’s intervention in the historical

<sup>209</sup> Miranda Fricker, *Epistemic Injustice* (2007), p. 2.

<sup>210</sup> Barney Afako, ‘Foreword’, p. xv.

Mbeki narrative, the novel equally participates in the wider “national project of remapping collective memory at work in post-Apartheid literature”.<sup>211</sup>

It is clear that Mbeki’s reputation as cold and aloof is a narrative that contributors to *The Thabo Mbeki I Know* are keen to redress. For example, contributors frequently digress from their narratives to emphasise their experiences of the former President’s conviviality and approachability: “Mandela had an aura that overwhelmed people and so did Thabo Mbeki”<sup>212</sup>; “Thabo Mbeki has this amazing ease with people [and] ability to fit in at any level”<sup>213</sup>; “I think [his sense of fun and enjoyment] is very important to note because people think that, from a young age, he was always a very serious person, which is just not true, not even in his old age. He loved to party [and] He denies it but, hell he can sing!”<sup>214</sup> Others strive to reframe his perceived seriousness in a more affirmative light, for example the late former President of Ethiopia, Meles Zenawi, recalling the delicate negotiation process that led to the establishment of NEPAD, acknowledged that “[Mbeki’s intellect] is a double-edged sword; he has sometimes been accused of being too scholarly and not charming enough. [But] I know of too many great ideas that have been defeated for lack of tact and patience for me to undermine the significance of what President Thabo Mbeki personally brings to the table”.<sup>215</sup>

Naturally, these authors’ personal connection to and potential stake in the reputation and legacy of Mbeki (i.e. their epistemic standing as sympathetic parties) must be taken into

<sup>211</sup> Shane Graham, *South African Literature after the Truth Commission* (2009), p. 4.

<sup>212</sup> Brigalia Bam, ‘Brigalia Bam’ (2016), p. 15.

<sup>213</sup> Tiksie Mabizela, ‘Tiksie Mabizela’ (2016), p. 24.

<sup>214</sup> Essop Pahad, ‘Essop Pahad’ in *The Thabo Mbeki I Know*, ed. Sifiso Mxolisi Ndlovu and Miranda Strydom (Johannesburg: Picador, 2016), p. 92.

<sup>215</sup> Meles Zewani, ‘Meles Zewani’ in *The Thabo Mbeki I Know*, ed. Sifiso Mxolisi Ndlovu and Miranda Strydom (Johannesburg: Picador, 2016), p. 49.

account when evaluating their accounts. Frank Chikane is assiduous, almost zealous in acknowledging how his proximity to the issues is likely to render him in some eyes as an unreliable witness. His narrative is imbued with awareness of the weak value of his account in the “economy of credibility”.<sup>216</sup> Understanding that Mbeki’s place in the dominant narrative has been cemented, he thus frames his writing as a form of testimony, which is a genre connoting moral rectitude and obligation:

Those of us who were close to the controversy have a responsibility to tell the story and leave it to the listeners or readers to judge ... In any story there are historical bits and gaps that can only be filled or completed by those who witnessed or had a direct experience of it.<sup>217</sup>

While ensuring he is protected by the subjectivity of individual memory, Chikane also emphasises his “direct” access to the events to qualify his account above those of other commentators or analysts. His bookending of each chapter with knowing extenuations of this kind is reminiscent of techniques used by the earliest English writers of prose fiction to enhance their narratives’ claims to truth.<sup>218</sup> Historians of the novel point out that the genre emerged at post-Renaissance moment following “a period of cognitive and social uncertainty”, in which “two fundamental oppositions – between the concepts of true and false and right and wrong” had led to a cultural crisis over the moral purpose and signification of narrative.<sup>219</sup> A similar moment could perhaps be identified in the South African landscape, wherein the 1999 Truth and Reconciliation Commission had similarly destabilised traditional

<sup>216</sup> Miranda Fricker, *Epistemic Injustice* (2017), p. 1.

<sup>217</sup> Frank Chikane, *The Things That Could Not Be Said* (2013), p. 254.

<sup>218</sup> As the novel was emerging as a genre, it lacked literary pedigree compared to factual accounts. Therefore “early modern novelists [...] strived to enhance the status of their works, [often titling] their novels ‘histories’ or ‘memoirs’ ... They situated their texts within discourses that society endowed with truth-bearing ability” (Marco Codebo, *Narrating from the Archive: Novels, Records and Bureaucrats in the Modern Age* (Vancouver: Fairleigh Dickinson University Press, 2010), p.50).

<sup>219</sup> Ibid, p. 22.



conceptualisations of the relationship between truth and justice, with the Archbishop Desmond Tutu stating at the outset of the highly public[ised] proceedings that “[t]he purpose of finding out the truth is not in order for people to be prosecuted. It is so that we can use the truth as part of the process of healing our nation”.<sup>220</sup>

Another stylistic strategy of these early novelists, also detectable in Chikane’s writing, is to persuade the reader to understand that what follows is being communicated for the benefit of society rather than the personal glory of the author,<sup>221</sup> and therefore that it is not in the interest of the author to fabricate or exaggerate his story. Chikane repeatedly stresses the danger and threats that he disregarded in order to share his witnessing of extraordinary historical events, and with repeated recourse to the rhetorical question, pre-emptively raises and resolves criticisms of his authority to write his account of the events:

...are there no risks in writing about such a controversial matter? The answer was emphatically, ‘Yes’, huge risks. This was followed by another question about whether it would help if someone who was in the office of Mbeki during this controversy wrote or spoke about it [...] Yes, because those who were close to the matter could help the national and international public to understand the story better.<sup>222</sup>

His portrait of Mbeki describes a man who is rigorous to the point of excess. He recalls how, as Deputy President, Mbeki was enthusiastic “to ensure that all public servants were not only conscious of the challenge but were part of the campaign to raise consciousness”<sup>223</sup> about HIV/AIDS, contradicting understandings that Mbeki was the key obstacle within

<sup>220</sup> Desmond Tutu, quoted in Martha Minow, *Between Vengeance and Forgiveness: Facing History After Mass Atrocity* (Boston: Beacon, 1998), p. 127.

<sup>221</sup> Christian humility...

<sup>222</sup> Frank Chikane, *The Things That Could Not Be Said* (2013), p. 253. Mark Gevisser

<sup>223</sup> Ibid, 258.

government; he “checked daily or whenever we met [that Chikane was wearing his red ribbon]. I felt quite harassed as he made sure of it”.<sup>224</sup> Later, having personally researched into the different conditions of prescription for different countries and associated risks, “Mbeki’s view was that many medical practitioners had not sufficiently familiarised themselves with HIV/AIDS”.<sup>225</sup> It is not hard to see why - Chikane’s text does not say but perhaps implies - that some among the medical establishment found it infuriating to see a politician not only overstepping his remit, but critiquing and undermining their ability to work within their own.

In the final appraisal, Chikane communicates his view of Mbeki as misunderstood and ultimately a (tragic) victim of external and internal forces:

It is clear that Mbeki embarked on the journey to combat HIV and AIDS from conventional orthodox perspectives. On the way he hit a number of hurdles, some of which were fatal. The first was the use of double standards in prescribing toxic drugs to poor people. The second were the emotional responses to the crisis, which did not make rational sense to him. Thirdly, he believed that he was being denied the right to question conventional wisdom as well as advance the search for solutions to one of the most challenging problems facing humanity [...] But the journey ended with him being firmly labelled a denialist and dissident, an enemy of the pharmaceutical companies, a detested person by those who campaigned for government to make antiretroviral drugs available.<sup>226</sup>

In his view, Mbeki has been discursively transformed into a one-dimensional character, an ‘enemy’ and villain, in order to serve a simplistic story. However, although apparently critiquing the way that “[i]n the case of HIV and AIDS the verdict has been passed and one is

<sup>224</sup> Ibid, 259.

<sup>225</sup> Ibid, 268.

<sup>226</sup> Ibid, p. 278.

either on the side of Mbeki or not. No one is allowed to think differently or take the middle ground”,<sup>227</sup> Chikane’s account of Mbeki as heroic crusader against injustice does not itself escape these epistemic constraints.

Imraan Coovadia’s fifth novel, *Tales of the Metric System* (2014), presents itself as a self-aware tilt at a national history. Comprised of ten vignettes of South African society over a forty-year period, *Tales of the Metric System* allows the reader to witness ten moments in time, spread out from 1970, during the height of Apartheid, to the fanfare of the 2010 soccer World Cup. Through its interweaving of high and low politics across a period of four decades, the novel “aims for a Tolstoyan ideal”.<sup>228</sup> Each tale can stand alone: however, the plots are linked by the threads of recurring characters who weave in and out of view. These characters are a mixture of wholly invented figures and recognisable fictive versions of actual historical persons. In some cases, this familiarity produces an intertextual experience, with certain plots recognisably modelled on or composites of real events that readers may have first encountered in newspapers or history books. In the novel, the author’s perspective on the ‘AIDS denialism’ controversy is conveyed through his characterisation of a certain President identified as ‘the Chief’.

Ronit Frenkel has pointed out that the timeframe of the novel is personally as well as politically revelatory, being overlaid precisely on the author’s life.<sup>229</sup> The opening year of the novel, 1970, marks both Coovadia’s birth year and South Africa’s adoption of the

<sup>227</sup> Ibid, p. 254.

<sup>228</sup> Jeanne-Marie Jackson, ‘The South African Novel of Ideas’ (2015), <https://nplusonemag.com/online-only/book-review/the-south-african-novel-of-ideas>, [Accessed 28<sup>th</sup> August 2018]

<sup>229</sup> Ronit Frenkel, ‘Imraan Coovadia’s Metonymic Aesthetics and the Idea of Newness in the South African Cultural Imaginary’, *Current Writing: Text and Reception in Southern Africa*, 28(1), 2-11. Doi: 10.1080/1013929X.2016.1170498

decimalised metric system and Rand – a process that represented modernisation yet at the same time the increasing inwardness of the Afrikaner nation, as the switch was intended to symbolise their rejection of Britain’s imperial currency. The idea of the metric system is employed throughout the novel as an extended metaphor for changes in consciousness and values: “what could be defined, counted and exchanged”.<sup>230</sup> The novel thereby seems to encapsulate Keightley and Pickering’s coinage of a ‘mnemonic imagination’, i.e. the use of imaginative processes to “help us integrate memories into a relatively coherent pattern of meaning ... and creatively transform memory into a resource for thinking about the transactions between past, present and future”.<sup>231</sup> As it relates unflattering episodes from South African history, the underlying conceit also reminds us about the possibility that oppressive values and categories of social being can be transformed and made obsolete.

An additional pertinent biographical detail is that Imraan’s father is Hoosen (‘Jerry’) Coovadia, an anti-Apartheid struggle veteran and academic paediatrician who became one of Mbeki’s most high-profile detractors over the AIDS issue.<sup>232</sup> Coovadia’s ground-breaking medical research, particularly on MTCT of HIV, was a factor in his appointment as Chairperson of the National Advisory Group on HIV/AIDS and STDs from 1995 to 1997 and his election as the Chairperson of the 2000 IAIDS Conference in Durban. In these roles, he campaigned actively for antiretroviral treatment provision, incurring threats from the ANC in the process.<sup>233</sup> Coovadia was personally acquainted with Mbeki, having met him along with

<sup>230</sup> Imraan Coovadia, *Tales of the Metric System* (Umuzi: Cape Town, 2014), p. 132.

<sup>231</sup> Emily Keightley and Michael Pickering, *The Mnemonic Imagination: Remembering as Creative Practice* (Hampshire: Palgrave Macmillan, 2012), p. 1.

<sup>232</sup> A profile of Coovadia published in *The Lancet* in 2009 describes him as a “giant of medicine in South Africa” and “like a Nelson Mandela in health” (Clare Kapp, ‘Hoosen Coovadia: an icon of South African health’ (2009), <[https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(09\)61581-6/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(09)61581-6/fulltext)>, [Accessed 28<sup>th</sup> August 2018])

<sup>233</sup> Clare Kapp ‘Hoosen Coovadia’ (2009), no pagination.

Essop Pahad, Oliver Tambo, Nkosazana Dlamini-Zuma and other ANC members during their time in exile in the UK, and reportedly found it “exceptionally hard” to challenge the ANC Party to which he had been loyal for decades.<sup>234</sup> These experiences must have been formative to the younger Coovadia, and arguably contributed to his sense of how integral the epidemic has been to the country’s political development, which is reflected in how it is foregrounded among other historical markers in the novel including political assassinations, experiences of exile among liberal South Africans during the 1980s and early 1990s, the rise in crime that accompanied the breakdown of Apartheid authority and the public extravaganzas of the 1995 Rugby World Cup and 2010 Football World Cup. It is almost certain that they would also have incubated the epistemic standing from which Mbeki is depicted in the novel, so that “[t]he failure of both the Mandela and Mbeki administrations to respond meaningfully and proactively to the AIDS crisis is [...] written over the idealised political possibilities of the transition”.<sup>235</sup>

The protagonist of the tale set in and titled ‘2003’ is the character Sparks, whose real-life counterpart ‘Parks’ Mankahlana was Mbeki’s spokesman and public face of his stance on HIV/AIDS (who told reporters that the Durban Declaration would be consigned to the dustbin). Mankahlana passed away aged 36 in October 2000 from what many speculated to be an AIDS-related illness, sparking pressure from activists for the ANC to publicly disclose his cause of death. Coovadia’s tale, set anachronistically three years later, portrays the last day in the character Sparks’ life, during which he is visited by the President – ironically

<sup>234</sup> South African History Online (SAHO), ‘Professor Hoosen Mahomed ‘Jerry’ Coovadia’, <<https://www.sahistory.org.za/people/professor-hoosen-mahomed-jerry-coovadia/>> [Accessed 1<sup>st</sup> September 2018]

<sup>235</sup> Andy Carolin, ‘Imraan Coovadia’s Post-transitional Palimpsest’, *Current Writing: Text and Reception in South Africa*, 28(1), (2016) p. 49.

referred to as his “principal physician”.<sup>236</sup> As the character is rendered speechless by the advanced state of his disease, we access his consciousness through the free indirect style that runs throughout the novel while others speak to him or within his hearing. The effect is an ironic juxtaposition of Sparks’ inner monologue of suffering and the oblivious bluster of the ‘President’:

- Look how you’ve improved since we stopped the antiretrovirals. You are off the poison and you are coming back from the dead. [...] Thanks to your bravery, we have exposed the lie of the infectious hypothesis. The only thing we must not allow for the newspapers to twist the story. The information about your case must come through the Presidency, fully controlled. Otherwise Jimmy Carter will be on my head. What’s that? Are you trying to say something? Speak up.<sup>237</sup>

The story is clearly intended to satirise Mbeki, suggesting an irrational and paranoid personality, more concerned with external opinion rather than reality. One enigmatic stylistic decision Coovadia makes in *Tales of the Metric System* is to give all of the characters the same terse speech patterns as the narrator: an effect heightened by his use of unobtrusive dashes instead of more conventional speech marks. This collective tone of voice weakens distinctions between the personalities of different characters – a curious effect considering how widely they range in terms of socio-economic, cultural and linguistic backgrounds. Thabo Mbeki, in particular, is recognised for his eloquence and rather mannered verbosity; indeed, in his collection of essays *Transformations* (2012), Coovadia had complained that “the more direct the problem he encounters, the more abstract, allusive and indirect his

<sup>236</sup> Imraan Coovadia, *Tales of the Metric System* (2014), p. 289.

<sup>237</sup> Ibid, p. 304.

language”.<sup>238</sup> The uniformity of characters’ speech might be intended, like the disappearance and reappearance of characters, to disrupt “the readers’ emotional or sensory attachments and [draw] attention instead to the book’s design”.<sup>239</sup> In the case of Coovadia’s portrait of Thabo Mbeki, however, it is possible that the dialogic characterisation is also intended to alter the former President’s image, particularly as it is paired with the narrative’s evocations of brutality and callousness - (“The chief came and stood behind the wheelchair. He put his hand on the patient’s neck. Sparks could imagine the chief starting to stifle him with the pillow”)<sup>240</sup> - that contrast with the diligent, mannered Mbeki that emerges from other portraits.

In *Tales of the Metric System*, AIDS is not invoked to increase empathy or understanding for people living with the disease: Sparks is a figure of absurdity, who willingly stops life-saving treatment out of misguided faith in his master, while the other HIV-positive character, Vish, is a rather thinly-drawn stereotype who features only for a few pages. In this sense, although the novel conveys the epidemic through individual characters living with HIV/AIDS, I consider it as representing a narrative of ‘disease’ more than of ‘illness’. AIDS here is a plot device employed to paint a picture of a political zeitgeist in which, Coovadia implies, the principles of science, reason and democracy have been hijacked. In a panel delivered at the Goethe-Institut in Johannesburg in May 2017, after reading from ‘2003: Sparks’, Coovadia told the audience that writers should resist the urge for “justice and revenge”, going on to describe his ‘more modest’ idea of what writing should be: “a constructive, additive

<sup>238</sup> Imraan Coovadia, *Transformations: Essays* (Cape Town: Umuzi, 2012), p. 80.

<sup>239</sup> Jackson, Jeanne-Marie. ‘The South African Novel of Ideas’ (2015), <https://nplusonemag.com/online-only/book-review/the-south-african-novel-of-ideas> [Accessed 7<sup>th</sup> September 2018]

<sup>240</sup> Imraan Coovadia, *Tales of the Metric System* (2014), p. 304.

pursuit”.<sup>241</sup> This statement might suggest that he views this fictional portrayal as a contribution to collective memory, supported by the words of a character in *Tales of the Metric System*: “novels are more important than ever [...] They allow us to step back and see where the history is taking us”.<sup>242</sup> The discussion suggests that both Coovadia and Chikane hope, in different ways, to make a narrative intervention in the political reputation of Mbeki, through texts which future generations will use to understand the recent past in the country’s present.

## Conclusion

Thabo Mbeki continues to loom large in contemporary South African literature and writing, often in subtler forms than in the texts discussed above: Daniel Lehman for example has suggested that Gavin Hood’s Oscar-winning film *Tsotsi* (2006), in which the titular teenage gangster lives a life of street violence, “results in a significant cultural indictment of Mbeki’s economic and HIV policies”.<sup>243</sup> While the film’s plot itself does not foreground AIDS, Lehman argues that by updating the story from its original Apartheid-era setting to the contemporary moment, Hood “introduces an AIDS discourse”<sup>244</sup> in which *Tsotsi* is understood as a secondary victim: in this reading, his mother’s fatal lack of access to ARVs directly implicates the health policies of President Mbeki’s ANC between 2000-2003.<sup>245</sup> This

<sup>241</sup> Personal notes (2017).

<sup>242</sup> Imraan Coovadia, *Tales of the Metric System* (2014), p. 133.

<sup>243</sup> Daniel Lehman, ‘Tsotsi Transformed: Retooling Athol Fugard for the Thabo Mbeki era’, *Research in African Literatures*, 42(1), 87-101, (2011), p. 87.

<sup>244</sup> *Ibid*, p. 91.

<sup>245</sup> Hood’s screenplay was adapted from a short story by the anti-Apartheid playwright Athol Fugard, written between 1958 and 1960. As such, the terminal illness that kills *Tsotsi*’s mother in the original narrative would probably have been tuberculosis, another chronic disease endemic to South Africa with political significance.



link between HIV/AIDS and the economic fortunes of South Africa and its citizens will be explored in further detail in the following chapter, including through a discussion of Masande Ntshanga's 2014 novel *The Reactive*, whose plot is also circumspectly compelled by early ART policy in South Africa.

In 2016, Mbeki himself waded into the discursive battleground over his reputation, publishing an open letter in which he reiterated that he had never denied the link between HIV and AIDS, but wanted to interrogate the relationship between the virus and the syndrome: "This false accusation was made by people who benefited from trumpeting the slogan 'HIV causes AIDS' as though this was a religious edict".<sup>246</sup> Christian terminology around denial, heresy and orthodoxy have been rife in the narratives that have emerged in response to the HIV/AIDS scandals, in a way that is perhaps indicative of the influence of the religion over the founding of the new South Africa (for example, how Archbishop Desmond Tutu's Truth and Reconciliation Commission – an attempt to produce an "institutionalized set of rhetorics" for the democracy<sup>247</sup> - promoted a distinctly Christian iconography of forgiveness, despite the fact that the language of spiritual healing is "foreign" to the original model of truth commissions and that the new nation professed to be both multi-racial and

<sup>246</sup> Thabo Mbeki, 'A brief commentary on the question of HIV and AIDS' (2016), <[https://www.unisa.ac.za/static/corporate\\_web/Content/tmali/documents/A%20brief%20commentary%20on%20the%20question%20of%20HIV%20and%20Aids.pdf](https://www.unisa.ac.za/static/corporate_web/Content/tmali/documents/A%20brief%20commentary%20on%20the%20question%20of%20HIV%20and%20Aids.pdf)> [Accessed 7<sup>th</sup> September 2018]. Mbeki is likely attempting to make an argument similar to that of Susan Sontag, when she wrote: "Strictly speaking, AIDS – acquired immunodeficiency syndrome – is not the name of an illness at all [...] though not in that sense a single disease, AIDS lends itself to being regarded as one – in part because unlike cancer and like syphilis, it is thought to have a single cause" (Susan Sontag, *AIDS and its Metaphors* (1988), p. 16). Again, whether Mbeki's commentary was appropriate is questionable. NGOs such as the TAC and Groundup were indignant at his "semantic games", arguing that "The 'S' in AIDS stands for syndrome [so] Mbeki is saying HIV cannot cause AIDS" (Nathan Geffen, 'Mbeki confirms he is an AIDS denialist', <<https://www.groundup.org.za/article/mbeki-confirms-he-aids-denialist/>> [Accessed 1<sup>st</sup> September 2018]).

<sup>247</sup> Katherine Elizabeth Mack, *From Apartheid to Democracy: Deliberating Truth and Reconciliation in South Africa*, (University Park, Pennsylvania: Penn State Press, 2014), p. 125.

multi-faith.<sup>248</sup> Indeed, the Reverend Frank Chikane even compared the HIV/AIDS controversy in Mbeki's life to Albert Nolan's description of the crucifixion as an event in the life of Jesus which became "such a dominant factor in his life that it became difficult to know his life before or outside this event".<sup>249</sup>

Philip Strong notes that since epidemics present "such an immediate threat, actual or potential, to public order, it can also powerfully influence the size, timing and shape of the social and political response in many other areas affected by the epidemic".<sup>250</sup> Recent published texts in South Africa have recognised and sought to redress the narratives they see to be solidifying around the controversies of the early 2000s, which they variously consider overly to malign or exonerate the character and motivations of the second President of South Africa, Thabo Mbeki. Despite the plethora of writers who have sought to rationalise Mbeki's actions during the late 1990s and early 2000s, there was arguably something visceral about his response that contributes to a continued ambiguity among the narratives. This chapter has explored how by becoming the protagonist of the HIV/AIDS story, Mbeki also presented a figure onto which many of the contradictions present in the post-Apartheid nation could be projected.

Through our reading of Chikane and Coovadia's recently published texts, we might understand these South African writers to be fundamentally concerned with the alignment

<sup>248</sup> Giuliana Lund writes that "In spite of its medical claims, the invocation of healing by the TRC actually reflects religious faith more than a concern for scientific evidence. This stance is quite unusual in the history of prosecutions and truth commissions succeeding mass atrocities [...] while the impact of scientific models is certainly important, the tremendous influence of Christian theology is equally pertinent in the case of South Africa, where the moral and political authority of the churches is deep and widespread" (Giuliana Lund, 'Healing the Nation' (2003), p. 104).

<sup>249</sup> Frank Chikane, *The Things That Could Not Be Said* (2013), p. 255.

<sup>250</sup> Philip Strong, 'Epidemic Psychology' (1990), p. 249.

between memory and national identity. Michael Rothberg writes that a tenet of much thinking on collective memory and group identity is that there are “winners and losers in the struggle for collective articulation and recognition”.<sup>251</sup> We can see these texts as partaking in an epistemic tug-of-war, in order to imprint their impressions of the period (which are themselves visibly imprinted with their writers’ individual experiences) onto the historical record or narrative. However, Rothberg continues, paying “attention to memory’s multidirectionality suggests a more supple social logic”.<sup>252</sup> The multidirectionality that he suggests emphasises the ultimately incommensurable co-existence of lived experiences, particularly when considering the relationship between collective memories and group identities. Taken together, narratives aiming to fix meaning within the “inextinguishable controversy”<sup>253</sup> over Mbeki and HIV/AIDS in South Africa may reveal more about the continuing epistemic silos in the country, from within which other groups may have at times seemed to fade into silence.

## **CHAPTER THREE – BREAKING THE SILENCE: PUBLIC AND HIDDEN TRANSCRIPTS**

Silence has meant that the truth about HIV/AIDS infection has been lost in the abyss, and that in its place dangerous and libellous reasoning has taken hold... [C]ollectively, stigmas associated with sex, possible witchcraft and the perceived living contamination with death or simply the impending fear of death, has meant that this silence has become normalized in South Africa.

<sup>251</sup> Michael Rothberg, *Multidirectional Memory: Remembering the Holocaust in the Age of Decolonization* (Redwood City: Stanford University Press, 2009), p. 5.

<sup>252</sup> *Ibid*, p. 5.

<sup>253</sup> Didier Fassin, *When Bodies Remember* (2007), p. xvi.

More than any other region, Africa ... stands out as the supreme receptacle of the West's obsession with, and circular discourse about, the facts of "absence", "lack" and "non-being", of identity and difference, of negativeness – in short, of nothingness.

Achille Mbembe, *On the Postcolony* (2001)<sup>254</sup>

Silences reverberate throughout the archive of knowledge about the epidemic in South Africa. From the earliest days of the HIV/AIDS crisis, the suppressing forces of stigma and discrimination have been powerful drivers of the epidemic worldwide and continue to prevent people from speaking openly. Denial, whether in the form of a coping mechanism, or about the epidemiological drivers of the disease, has affected both individuals and decision-makers, preventing them from taking available steps to diminish further transmission and increase treatment uptake of the virus.<sup>255</sup> Meanwhile, the effects of the ANC's government prevarications regarding the provision of ARVs continue to be felt today. These factors combined to produce an overriding impression of an intolerable silence. In this chapter, I explore some of the processes by which 'silence' has come to take on meaning in relation to HIV/AIDS in the context of post-Apartheid South Africa, and how it presents an implicit discursive backdrop to the texts that are discussed in later chapters of the thesis. I also reflect on what ideas about 'silence' in relation to HIV/AIDS reveal about the processes of narrative

<sup>254</sup> Lizzy Attree, *Blood on the Page* (2010), p. 11; Achille Mbembe, *On the Postcolony* (2001), p. 4.

<sup>255</sup> In South Africa, one of the most high-profile tragic examples of the potentially fatal effects of stigma is the 1998 murder of Gugu Dlamini, three weeks after she had publicly disclosed her positive status on the local radio on World AIDS day. (M Raubenheimer, 'AIDS activist murdered' (1999), Newsletter of the Women's Health Project, cited in Pieter Fourie, *The Political Management of AIDS in South Africa* (2006), p. 132.

and knowledge production, and the different forms of exclusions that they may activate.

As outlined in the introductory chapter, South Africa has a thriving and vocal civil society, which took action to counter both social fear and government failures. The epidemic and associated policy crises inspired the formation of the TAC in 1998, now one of the most significant advocacy organisations for PLWHA globally. The very existence of the TAC contradicts an image of passivity and repression, having taken the extreme and public action of pressing legal charges against their liberation movement's government in the High Court, on the grounds that the ANC was denying their citizenship fundamental human rights. Meanwhile, as is often the case with public health communication, message penetration was uneven in different regions. In contrast to Attree's account of silence about AIDS as "normalized", in 2003 the education researchers Claudia Mitchell and Ann Smith found that young people in cities were already feeling 'sick of AIDS' due to the oversaturation of information: "AIDS, AIDS, AIDS – that's all we ever hear".<sup>256</sup> Silences or evasion co-existed with, and were layered over and beneath, ubiquitous articulations of the epidemic, as for example recalled by Sisonke Msimang in her memoir *Always Another Country* (2017):

AIDS is everywhere. Every newspaper headline, every billboard. Suddenly it seems everyone is dying at once. Aunties are dying quietly and uncles are slipping away. No one wants to say what it is, even though we all know.<sup>257</sup>

<sup>256</sup> Claudia Mitchell and Ann Smith, "Sick of AIDS': life, literacy and South African youth', *Culture, Health and Sexuality*, 5.6, (2003), p. 513.

<sup>257</sup> Sisonke Msimang, *Always Another Country: A Memoir of Exile and Home* (Johannesburg: Jonathan Ball, 2017), p. 229.

Despite its prominence in the literature, the idea that silence is South Africa's chief reaction to the epidemic therefore obscures as much as it reveals. The anthropologist Jean Comaroff has argued that "the inaudibility of talk about AIDS is often less a matter of brute repression or secrecy than of complicated communicative practices in the context of radical uncertainty. Nuanced registers and indirect forms of speech flourish in a field haunted by the ubiquitous presence of the disease".<sup>258</sup> In this view, the silence around HIV/AIDS – so quickly and almost tritely observed in the region most heavily struck – is often a misnomer. Accentuating that silence may thus unwittingly produce barriers to understanding, by concentrating on an idea of negative space, which implicitly reinforces an assumed impossibility of communication, and this self-perpetuating identification of silences has 'real world' ramifications: it diverts theoretical and practical energies to battling a straw man - trying to understand why people will not think and act within an imposed set of norms - which could be used to better provide for the particularities of local needs. If the prevailing wisdom is that the greatest barrier to tackling HIV/AIDS is silence, the most urgent task at hand must be to bring knowledge and to discredit myths.<sup>259</sup> However, this can denote less the replacement of silence with language and reason, and rather the imposition of one discourse over another. David Dickinson discerns that although the AIDS epidemic is now abating in South Africa, "when it comes to behavioural change it seems that this has come about largely despite our efforts and not because of them [...] Indeed, it is possible that our intervention efforts have achieved little more than an enriched vocabulary of medical terms among the population".<sup>260</sup>

<sup>258</sup> Jean Comaroff and John Comaroff, *Theory from the South* (2012), p. 178.

<sup>259</sup> David Dickinson argues that the assumption that knowledge equals belief is a "mistaken view, upon which a multi-million-dollar AIDS education industry is based" (David Dickinson, *A Different Kind of AIDS* (2014), p. xxiii).

<sup>260</sup> David Dickinson, *A Different Kind of AIDS* (2014), p. xxvi.

In addition, as the epigraph from Achille Mbembe suggests, the identification of silence should be read in the context of a discursive tradition in which Africa is presented as a *problem*. As such, it is frequently deployed in a euphemistic way, being invoked to signify a range of problems including the lack of visibility of PLWHA; repression and censorship; negligence and political apathy; ignorance, denial(ism) and taboo; and the lack of HIV/AIDS narratives and literature. (Mbembe writes that when it comes to Africa, “correspondence between words, images, and the thing itself matters very little. It is not necessary for the name to correspond to the thing, or for the thing to respond to its name”).<sup>261</sup> The emphasis on silence therefore seems to place the source of the epidemic within the epistemic capacity of the afflicted, conflating the virus’ prevalence with a lack of will or care. Diagnoses of silence are therefore not unrelated to the unevenness with which knowledge(s) from Africa are discerned and disseminated, and my investigation of silence in this chapter exposes ways in which these contributions can be left unheard. Because the worldview and political commitments of institutions that guard over the production and transfer of knowledge can variously reveal or conceal aspects of social reality, as Gayatri Spivak (1988) has argued, knowledge expresses the interests of its producers.<sup>262</sup> The maintenance of hegemonic regimes of truth underwrite what I call a ‘discursively constructed silence’ around the epidemic in South Africa, which occurs in tandem with colonially-inflected constructions of the continent as vacant and thus ripe for appropriation and salvation. I use this seemingly paradoxical term to distinguish the undeniable existence of silences relating to HIV/AIDS – whether stemming from social taboo, denial, or personal discretion - from silences discursively produced through power-laden acts of misreading or selective omission.

<sup>261</sup> Achille Mbembe, *Critique of Black Reason* trans. by Laurence DuBois (Durham, London: Duke University Press, 2017), p. 49.

<sup>262</sup> Gayatri Spivak, *Can the Subaltern Speak?* (Basingstoke: Macmillan, 1988).

## Public and hidden HIV/AIDS transcripts

In his landmark work *Domination and the Arts of Resistance* (1990), James Scott observed that discourses are universally altered by power - or more specifically whether power is present or absent. Discerning a structural kinship between disparate scenarios in which one group dominates another through an “institutionalized arrangement for appropriating labor (sic), goods and services from a subordinate population”,<sup>263</sup> he finds that “the process of domination generates a hegemonic public conduct and a backstage discourse consisting of what cannot be spoken in the face of power”.<sup>264</sup> Behind a protective façade, the subjugated group has a ‘hidden transcript’ which allows them to express their authentic responses. The public transcript meanwhile functions to affirm the legitimacy of the inequality, emphasising the dominant groups’ benevolent motives; consequently, the dominant groups will often have a hidden transcript of their own (an example that Scott provides is that of tax loopholes, which enable systems of skewed wealth accumulation to maintain a patina of legality and egalitarianism). As such, the public transcript is a collaborative production, although it is of course important that this fiction is imposed in one direction with the assistance of coercion and pressure.

In relation to HIV/AIDS, the contrast between ‘silence’ and ‘discursively constructed silence’ may be further refined by distinguishing between failures to speak and failures to hear.

<sup>263</sup> James Scott, *Domination and the Arts of Resistance* (1990), p. x. Following as he does a Marxist tradition, Scott’s analysis of power relations tends to adhere to a materialist line of inquiry, with key case studies constituting systems of slavery, serfdom and caste/class exploitation, although he also examines, albeit in less depth, forms of domination specific to other identities like patriarchal domination and racism.

<sup>264</sup> Ibid, p. xii.



Recent work by the sociologist Susan Watkins is revealing of the process by which the latter may occur. Over a period of almost a decade, she employed community members in rural areas of Malawi to keep journals, noting any instances when they heard HIV/AIDS being discussed in some way, with the aim of learning more about how people targeted by health education campaigns respond to and make sense of those interventions. This method, which she has termed ‘hearsay ethnography’,<sup>265</sup> captured data showing why identifying an absence of a talk should not be determined by utterance but also reception and domain, by making potentially clear how redolent the research process is with the politics of sociality. As Watkins explained to an interviewer:

The prevailing wisdom [among the prevention community] was that people don’t talk about AIDS. It’s a taboo topic. They don’t talk about sex. And the Malawian elites, who work for the NGOs, said that as well. No, our people don’t talk about AIDS and don’t talk about sex. But of course, we found out right away that they do. And they talk a lot. And they say very pertinent things to HIV prevention.<sup>266</sup>

This revelation would of course be no such thing to the people Watkins is speaking of. Her work thus provides an example of “discourse that takes place “offstage”, beyond direct observation by powerholders”.<sup>267</sup> The fact that the professional class employed at the NGOs accepted the prevailing wisdom may also align with Scott’s point that it can be advantageous to perform agreement with the public transcript; it is in the interest of NGOs wishing to obtain repeat funding to feedback data which fits with international donor priorities. The US

<sup>265</sup> Susan Cotts Watkins and Ann Swidler, ‘Hearsay Ethnography: Conversational Journals as a Method for Studying Culture in Action’, *Poetics*, 37(2), (2009), 162-184.

<sup>266</sup> Sarah Koenig, ‘Gossip’ (2011), <<https://www.thisamericanlife.org/444/transcript>> [Accessed 1<sup>st</sup> September 2018].

<sup>267</sup> James Scott, *Domination and the Arts of Resistance: Hidden Transcripts*, (New Haven: Yale University Press, 1990, p. 4. Scott’s concept of a transcript hidden in plain sight may describe social circumstances where power-holding groups (e.g. researchers) are not literate in some of the languages current in the population.

President's Emergency Plan for AIDS Relief (PEPFAR) is one of the biggest funders of AIDS programmes, supporting over 14 million people worldwide (PEPFAR 2018). Under Republican Presidents George W. Bush (2001 – 2009) and now Donald Trump (2017 – present), the Mexico City Policy or 'Global Gag Rule' requires recipient organisations to prove they do not advise or discuss abortions or else lose all US funding. Imposed research objectives with ideological attachments of this kind can reduce researchers' capacity to address and even perceive the totality of PLWHA's experience.

Corroborating a certain readiness to perceive silence around HIV/AIDS in the postcolony even in the midst of abundant discourse, the Botswanan American-educated scholar Bagele Chilisa has recorded how "[w]hen people give their meanings of HIV/AIDS based on their life experiences and perceptions of reality, Western-trained researchers - often operating within the dominant HIV/AIDS language - label them as misconceptions or cultural ignorance".<sup>268</sup> Communities which stand to benefit from global HIV/AIDS research programmes and resources can lose faith when faced with those who refuse to take seriously or grant authority to their knowledge, and who sense a repetition of familiar power/knowledge oppression. Grace Musila has similarly noted during her analysis of a miscarriage of justice in Kenya that "local textualities [may] remain inaccessible to the instruments of Western modernity", pointing out the unquestioning faith of the injured party in familiar systems ironically prevented him from unearthing the truth.<sup>269</sup>

<sup>268</sup> Bagele Chilisa, 'Educational research within postcolonial Africa' (2005), p. 669.

<sup>269</sup> Grace Musila, *A death retold in truth and rumour: Kenya, Britain and the Julie Ward murder* (Woodbridge, Suffolk: James Currey, 2015), p.29.

Discursive constructions of silence also function euphemistically, to signify suppression of the freedom of speech (at personal or political levels), denial, passivity, lack of education / illiteracy, taboo or superstition – which are then depicted as obstacles to the well-meaning endeavours of the enlightened or educated.<sup>270</sup> Failure to read these nuances stems from an inherited imbalance of epistemic power that privileges Western frameworks and the related tradition of problematizing the global south. It follows that such diagnoses often produce - in the first instance – solutions in the form of Western intervention. The anthropologist Danny Miller’s argument that contemporary neoliberal economics has given itself “the legitimate authority to transform the world into its own image”, indicates how intellectual models of how the world should behave can effectively over-ride what actually happens, categorising local particularities as distortions or anomalies, and thus eliminating the need to engage with them critically.<sup>271</sup> Indeed, the fervour of the international attempt to bring Mbeki in line with AIDS orthodoxy arguably silenced the need for supplementary, localised research into the realities of people affected by HIV/AIDS in South Africa and in Africa and other poorer contexts. The effect of this discursively produced silence was noticed by Paul Farmer when he wrote in the aftermath of the International AIDS Conference that:

Meanwhile, real AIDS issues go unnoticed. According to one recent scholarly study, ‘Somewhat surprisingly, towards the end of the second decade of the AIDS pandemic, we still have no good evidence that primary prevention works [...] This should have triggered the

<sup>270</sup> A typical example comes from a recent column in the influential British tabloid newspaper *The Sun*, originally titled “Charities are doing their best to educate and inform but they face prejudice and misinformation” even as the columnist repeats misinformation in the form of unsubstantiated stereotypes (“Too many African men with HIV simply will not wear a condom”) anecdotal evidence and rumours (“appalling acts of rape have been committed on children, in the mistaken belief that having sex with a virgin will cure the disease and give sufferers immunity”). (Lorraine Kelly, <<https://www.thesun.co.uk/archives/news/741968/why-hollywood-star-with-hiv-is-lucky/>> [Accessed 2nd September 2018]. For a study regarding the likely falsity and origins of the latter, see Helen and Rachel Jewkes ‘The myth of the virgin rape myth’, *The Lancet*, 364(9699), (2009).

<sup>271</sup> Danny Miller, ‘A theory of virtualism’ (1998) cited in Mike Crang, Phil Crang and Jon May, *Virtual Geographies: Bodies, space and relations* (London: Routledge, 1999).

mother of all [debates]. But no. The AIDS community was busy focusing on Mbeki [who] dominated the whole bandwidth of attention.<sup>272</sup>

The various theorists and researchers cited here are united by their undertaking of identifying and recording the existence of discourses or transcripts about HIV/AIDS in Africa that tend to be ‘hidden’ to the dominant gaze. Together, their arguments imply not that biomedical expertise is invalid or inappropriate, nor do they make a case for medical relativity. What they share is a concern that diverse epistemic frameworks are needed in order to resist ‘the error of sameness’,<sup>273</sup> in which some people and communities are obliged to accept a one-size-fits-all solution not designed with their needs and experiences in mind. Global structures sedimented by epistemic injustice are thus shown to problematise these other groups, so that their silence is more willingly apprehended than articulations that seriously contest the dominant narrative.

Scott’s concept of the ‘hidden transcript’, only visible to those who have access to the backstage spaces of social life, is instructive for my interrogation of silence in South Africa. He distinguishes that while this “hidden transcript” is always present and used by the subjugated to express authentic responses to the experience of domination, they will meanwhile dissemble compliance with and endorsement of the “public transcript” whenever in the (dangerous) presence of those who wield power. The public transcript therefore usually functions to affirm the legitimacy of the unequal power structure, emphasising the dominant group’s benevolent motives; consequently, the dominant group will usually have a hidden

<sup>272</sup> Paul Farmer, ‘AIDS Heretic’ (2001), no pagination.

<sup>273</sup> Bagele Chilisa, ‘Educational research within postcolonial Africa’ (2005), p. 671.

transcript of their own through which they can express their apprehension of reality. In order to maintain the stability of the social structure, both groups are usually careful to keep these discourses from one another. It can therefore be in *both* groups' best interest to pretend to believe the other's performance of the public transcript: for the dispossessed, to avert further discipline and for the powerful, to prevent a crack in the facade. Scott writes that it is one of the most "rare and dangerous moments in power relations" when a hidden transcript is openly declared.<sup>274</sup>

In the case of the HIV/AIDS epidemic in South Africa, the public transcript might be understood to be what David Dickinson calls "the medical-human rights framing", around which "an AIDS establishment of scientists, doctors, social scientists, health departments, international and national NGOs and activists has coalesced".<sup>275</sup> While this may seem counter-intuitive, due to the fact that these players undeniably work on behalf of the vulnerable, this framing is also aligned with a series of power relations that Thabo Mbeki attempted to make explicit during his time as President. The public transcript constructed by the Global North is one in which those nations are at the forefront of combating material poverty and health inequities through their delivery of aid and loans to resource-poor areas (e.g. Harrison, 2010; Sastry and Dutta, 2011).<sup>276</sup> However, this particular narrative over-rides alternative simultaneous accounts, where the same nations could be seen to have impeded the aims of international development efforts, including the legal measures taken by Big Pharma to prevent lower-income countries afflicted by HIV/AIDS from providing antiretroviral

<sup>274</sup> James Scott, *Domination and the Arts of Resistance* (1990), p. 6.

<sup>275</sup> David Dickinson, *A Different Kind of AIDS* (2014), p. 18.

<sup>276</sup> Graham Harrison. (2010), 'The Africanization of Poverty: A Retrospective on Make Poverty History', *African Affairs*, 109: 291-408; Shaunak Sastry and Mohan J Dutta, 'Postcolonial constructions of HIV/AIDS: meaning, culture and structure', *Health Communication*, 26(5), (2011), doi: 10.1080/10410236.2011.554166

treatment to their citizens (Smith and Siphon, 2006; Mbali, 2013);<sup>277</sup> the overall net loss of resources moving from Africa in the form of multinational companies' profits, debt payments, illicit financial flows to foreign tax havens, illegal logging and fishing and the 'brain drain' of skilled workers (Sharples et al, 2014);<sup>278</sup> or the 'securitisation of HIV/AIDS' in African countries rich in oil or strategically important to the military interests of the US.<sup>279</sup> As such, a corresponding silencing occurs whereby those social and geopolitical realities that contradict the self-image of powerful groups are made relatively unsayable: in Foucauldian terms, furnished with a less robust truth status.

By breaking the taboo of the AIDS establishment, and questioning the logic of global capitalism, Mbeki's speech at the 2000 IAIDS conference might be seen as one of the occasions when the public transcript is breached. His challenge to the international institutions and to "a world driven by a value system based on financial profit"<sup>280</sup> can be read as an attempt to uncover the hidden transcripts of the powerful. Namely, his statements insinuated that the public transcript of global human rights does not always translate into

<sup>277</sup> Raymond A. Smith and Patricia D. Siplon, *Drugs into Bodies: Global AIDS Treatment Activism* (Santa Barbara: Praeger, 2006); Mandisa Mbali, *South African AIDS Activism and Global Health Politics* (London: Palgrave Macmillan UK, 2013).

<sup>278</sup> Natalie Sharples, Tim Jones and Catherine Martin, 'Honest Accounts? The true story of Africa's billion-dollar losses' (2014), <[https://www.francophonie.org/IMG/pdf/honest-accounts\\_final-version.pdf](https://www.francophonie.org/IMG/pdf/honest-accounts_final-version.pdf)> [Accessed 1st September 2018]. The report was written on behalf of fourteen NGOs from the UK, Zimbabwe, Kenya, South Africa and Mozambique. In the report they dispute the "dishonest dialogue [reinforced] in the minds of the public that Africa is a problem that costs us money" (p. 5), showing how in fact the amount of financial resources leaving the continent far outstrips the amount of aid received. The authors estimate the net annual loss at \$58.2 billion, a sum which they note "is over one and a half times the amount of additional money needed to deliver affordable healthcare to everyone in the world" (p. 6)

<sup>279</sup> Stefan Elbe emphasises that efforts to frame the AIDS pandemic in terms of security are novel: the United Nations Security Council's meeting in January 2000 was unprecedented "in that the Council had never before considered an illness to pose a threat to international peace and security" (Stefan Elbe, 'AIDS, Security, Biopolitics', *International Relations*, 2005, 19(4), p. 403). Following Foucault, Elbe expresses concern that this biopolitical dimension "brings into play a set of potentially racist and normalizing social practices" (p. 403). See also Alan Ingram, 'HIV/AIDS, Security and the Geopolitics of US: Nigerian Relations', *Review of International Political Economy*, 14(3), (2007).

<sup>280</sup> Thabo Mbeki. 'Speech by Thabo Mbeki at the Thirteenth International AIDS Conference, July 9, 2000'.

actions that improve or protect the lives of the world's socio-economically disadvantaged. This was not an entirely unique point of view even then: as Paul Farmer wrote in 2001, linking the structural violence maintained through imposed social arrangements that prolong poverty to the flourishing of disease and suffering was “precisely the point many of us have tried to make, and though our views have not always been welcome, we haven’t been branded as AIDS heretics”.<sup>281</sup> However, Mbeki was constructed as the arch-denialist of HIV and an adversary of human rights and science, in a way that many commentators have surmised entrenched the battle lines between the government and activists in South Africa, in what can be seen as an effort to preserve the global public transcript on HIV/AIDS.

### **Silence is Death: global implications in the context of HIV/AIDS**

The word ‘silence’ has an especially marked resonance with regards to international HIV/AIDS discourse, the origins of which can be traced to the ‘Silence = Death’ slogan created by six activists in New York in 1987. This slogan became central to the later ACT UP campaign and is also the title of a 1990 documentary about the response of artists, including Keith Haring and Allen Ginsberg, to the epidemic. For these American activists and artists, silence stood for the fatal inaction, homophobia and the untenable prudishness that prevented open discussion of safe sex practices or condom distribution, encapsulated by then-President Ronald Reagan who “did not mention the word AIDS once until 1987” (Kalinga, 2014, no pagination).<sup>282</sup> The slogan was printed under a pink triangle, directly referencing the symbol

<sup>281</sup> Paul Farmer, ‘AIDS Heretic’ (2001), no pagination.

<sup>282</sup> Theodore Kerr writes of Ronald Reagan’s leadership at this time that “[h]is silence is so entrenched in the story of AIDS that to not mention it can feel like one is granting him absolution. And yet, simply mentioning his silence fails to grasp the complexity of what happened during his presidency” (Theodore Kerr, ‘AIDS 1969: HIV, History and Race’ (2016), no pagination). See also Bruce Nussbaum, *Good Intentions: How Big Business*

used by the Nazis to mark homosexual men in concentration camps (see Figures 1 & 2, overleaf). An equally famous poster produced by the group, headed ‘AIDSgate’, centred an image of Reagan with demonic pink eyes and the caption: “What is Reagan’s real policy on AIDS? Genocide of all non-whites, non-males, non-heterosexuals...” Their naming of silence was therefore devised to speak truth to power, and in the wake of that campaign, the word carries the sense of deliberate, government-sponsored, mass killing.



Figures 4 & 5: The famous SILENCE=DEATH poster (L) and the French version (R)

The powerful slogan was adopted by other ACT UP branches including in the United Kingdom and France. Ryan Conrad of the AIDS Activist History Project has however specified that “the taking up and general usage of Holocaust and genocide metaphors in

*and the Medical Establishment Are Corrupting the Fight Against AIDS* (New York: The Atlantic Monthly Period, 1990).



relation to the AIDS crisis is particularly American”, even as this framing was never free from controversy within the country itself.<sup>283</sup> Invocations of silence in relation to HIV/AIDS in South Africa can be seen to draw on activist frameworks both from the country’s recent struggle against segregation and racial oppression and from these “meaning-making metaphors ... of mass death and total destruction of queer lives” produced in the North American context.<sup>284</sup> As we have seen, Mbeki’s government also found themselves charged with genocide, medical Apartheid and criminal negligence in the public arena. As the TAC developed in alliance with patient organisations across the globe,<sup>285</sup> a shared language of protest developed. This language reinforced the representation of the AIDS debate as a tug-of-war between truth and error, good and evil.

At the same time, the power to whom truth needed to be spoken in the context of a postcolony such as post-Apartheid South Africa is surely distributed more uneasily. Though a world leader, Mbeki does not stand as a direct analogue to Reagan, given that the US President has agency not only to make decisions on behalf of his own country’s citizens but to determine outcomes for those in others (as in the legal action brought against the South African government for infringing on US industry profits). Without minimising his failures, it is important to recognise Mbeki’s ability to act in the interests of his population was circumscribed in ways that differentiate the South African story of HIV/AIDS from the

<sup>283</sup> Ryan Conrad, ‘Revisiting AIDS and its Metaphors’ (2016), no pagination. Conrad surmises that the reason for its resonance and circulation in the United States is rooted in two specific socio-historical conditions: the first being the large Jewish population who had fled there from a hostile Europe during the earlier decades of the twentieth century. The second was that unlike Europe, America lacked a national health care system, and this heightened the sense that treatment, care and prevention was being unjustly and avoidably withheld from already disadvantaged populations.

<sup>284</sup> Ibid, no pagination.

<sup>285</sup> Raymond A. Smith and Patricia D. Siplon, *Drugs into Bodies* (2006). Smith and Siplon document the 13th IAIDS Conference in Durban in July 2000 as a milestone in the development of a transnational treatment access movement, in particular that it afforded activists the opportunity to physically meet and share strategies.

Western one. Under neo-colonialism, the sovereignty outwardly embodied by heads of states screens their nation states' "entrapments within colonial matrices of modern global power" that continue to intervene in their economic systems and policies from afar.<sup>286</sup> Paul Farmer for instance contests that "if anything has curbed post-Apartheid South Africa's investment in social services, it has been outside advisers from the International Monetary Fund, the World Bank and other 'Western' advisers – the same lot, often, that deride him for his AIDS policy".<sup>287</sup> In this context, the patient-activists of Sub-Saharan Africa and Northern Europe or America may be horizontally aligned in solidarity but remain arranged on different echelons of a hierarchy of privilege, whereby the latter benefit from medical infrastructure and research that often thrives at the former's expense.<sup>288</sup>

In his 2011 essay, 'An Eerie Silence: Why is it so hard for South Africa to talk about AIDS?', Jonny Steinberg attributes what he identifies as a general unwillingness to discuss the epidemic within the population to "the agenda set by black South African nationalists",<sup>289</sup> producing as evidence not only Mbeki's objections against Western drug manufacturers but also the fact that in 1988, Cyril Ramaphosa - who was, at that time, the general secretary of the National Union of Mineworkers - had blocked the domestic publication of a sociological

<sup>286</sup> Sabelo J. Ndlovu-Gatsheni, *Coloniality of Power in Postcolonial Africa* (Dakar: CODESRIA, 2013), p. 1.

<sup>287</sup> Paul Farmer, 'AIDS Heretic' (2001), no pagination.

<sup>288</sup> The Global North continues to utilise the postcolony as a terrain for knowledge production, in which the researched populations participate unequally. Jean and John Comaroff argue that Africa is seen as a source "[a]bove all, of unprocessed data. These other words, in short, are treated less as sources of refined knowledge than as reservoirs of raw fact" (Jean Comaroff and John Comaroff, *Theory From the South* (2012), p. 1). Helen Epstein meanwhile wrote of the Ugandan context: "'Sometimes I don't know what I am doing here', the American doctor told me. But I did, and so did this doctor's employers. Conducting this trial in the US would have been much more expensive because the American patients would have required far better care. But ethical standards required that the pharmaceutical company needed only to ensure that the Ugandan patients received the standard of care in Uganda, which was very low indeed." (Helen Epstein, *The Invisible Cure* (2007), p. 14).

<sup>289</sup> Jonny Steinberg, 'An Eerie Silence' (2011) <<https://foreignpolicy.com/2011/04/25/an-eerie-silence/>> [Accessed 29 August 2018]

article that predicted AIDS would reach pandemic proportions in South Africa. Steinberg reports that Ramaphosa objected to the fact that “the research presumed black men to be promiscuous and thus was tinged with racism”, which, he notes, shows that “Mbeki was not necessarily the outlier he is often said to be”.<sup>290</sup> Nevertheless, his conclusion from these events leans not towards the likelihood that early sociology of HIV/AIDS, produced within the Apartheid system during the late 1980s, betrayed systematically pejorative attitudes, but that the black nationalist consciousness of the new governing party was puritanical, paranoid and repressive:

It has meant that South Africa was not really permitted to examine its own, private experience of AIDS, for to be black and to write about one’s sexuality or one’s illness was in many quarters considered an act of betrayal, as if one were delivering ammunition to Western racism.<sup>291</sup>

Instinctively, the equation of denial with silence became near-metonymic with Mbeki himself. He was held responsible for the wider phenomenon by having intimidated much of the government and medical community into unwilling silence: “Perhaps he was surrounded by sycophants, all too afraid to ‘speak truth to power’”.<sup>292</sup> Accounts from the time suggest that many indeed were prevented from speaking or acting, although others were sincerely convinced by Mbeki’s reading of the situation. In many ways, Mbeki’s government’s response was an over-exertion of political will rather than the indifference or inaction

<sup>290</sup> Ibid, no pagination.

<sup>291</sup> Ibid. Jonny Steinberg, ‘An Eerie Silence’ (2011), no pagination.

<sup>292</sup> Kerry Cullinan and Anso Thom, *The Virus, Vitamins and Vegetables*, (2009), p. 44.

actually shown by other authorities.<sup>293</sup> The perception of Mbeki as ‘silent’ on HIV/AIDS is also discernible in Lizzy Attree’s contention that “[u]nlike Mbeki”, Zimbabwe’s Robert Mugabe, “has at least spoken about HIV/AIDS”,<sup>294</sup> exemplifying how Mbeki’s refusal to speak the language of the medical establishment was transformed into a symbolic muteness that in turn overpowered the reality of his numerous speeches and publications. As those speeches diverged from official knowledge, they were disavowed to the point of narrative effacement.

Leaving temporarily aside judgements about the correctness of Mbeki’s estimations and actions, this process of muting is revealing. The *undesirability* of Mbeki’s stance, in its deviance from and challenge to the normative position at the time, was encountered with nullification. In this way, the refrain of silence can be linked to ideas of epistemic injustice and the tendency described by Achille Mbembe of Western culture to disaffirm African lived realities and social and intellectual autonomy. This suppression and obscuring of alternative knowledges has arguably inflated the sense of ‘silence’ and inaction around the epidemic – in Mbembean terms a ‘negative interpretation’ of events. Again, this is not to disavow the existence of silences relating to AIDS in South Africa, but to suggest that undue focus on identifying silence can be problematically utilitarian and ultimately counter-productive to humanitarian aims. Because ‘silence’ often euphemistically stands in for ignorance or illiteracy, it has the potential not only to demean the epistemic capacities of the subordinated,

293 In fact, indifference could have been preferable in some cases: the physician and paediatrician doctor Ashraf Coovadia recalls that on the matter of AZT, “we were, in a way, bending the non-existent rules [in order to import drugs to provide to patients]. In 1999, however, we received a message from the powers-that-be in the province telling us that we couldn’t use AZT, that it was not national government policy, and that we must stop” (Ashraf Coovadia, ‘Courting mortality: The fight to prevent mother-to-child transmission’, in *The Virus, Vitamins and Vegetables* ed. by Kelly Cullinan and Anso Thom (2009), p. 62).

294 Lizzy Attree, *Blood on the Page* (2010), p. 12.

but to be strategically deployed in ways that invalidate agency, giving others the right to make decisions on behalf of the people affected. For instance, the way that Attree (in the epigraph to this chapter) directly opposes the silence she describes to “truth” and “reasoning” reproduces - no doubt involuntarily - the kinds of colonial constructions of the Other that were so vehemently objected to by Thabo Mbeki - as one that cannot, should not, speak: as one who must be spoken for.

A key pillar in Mbeki’s objections to the pronouncements of the international medical community, which he saw as allied to the interests of the pharmaceutical corporations, was their denial of African intellectual/epistemic autonomy. When raising other explanations, some of which align with ‘hidden transcripts’ or suppressed narratives related to the pandemic, Mbeki received a response that he considered excessively emotionally charged and therefore suspect. It seems that Mbeki recognised that he was being silenced by being “downgraded and/or disadvantaged in respect of [his] status as an epistemic subject”<sup>295</sup>. In response, he emphasises the worth of African testimony, setting up the lived experience of people in “our country” as a foil to the shallow experience of many of the delegates who would experience only the luxurious conference centre and hotels, and makes a request for an flattened hierarchy of epistemic power:

Because of your heavy programme and the limited time you will spend with us, what you will see of this city, and therefore of our country, is the more developed world of which the WHO spoke [...] You will not see the South African and African world of the poverty of which the WHO spoke, in which AIDS thrives – a partner with poverty, suffering, social disadvantage and inequity.

<sup>295</sup> Miranda Fricker, *Epistemic Injustice* (2007), p. 53.

As an African, speaking at a conference such as this, convened to discuss a grave human problem such as the acquired human deficiency syndrome, I believe that we should speak to one another honestly and frankly, with sufficient tolerance to respect everybody's point of view, with sufficient tolerance to allow all voices to be heard.<sup>296</sup>

Nevertheless, in his position as a head of state giving a keynote speech at an international conference, Mbeki of course also represented a locus of power behind which, “backstage”, other voices proliferated. A common argument has been that Mbeki's views dissuaded ordinary South Africans from believing external information, or rather gave them free rein to believe in alternative theories. Didier Fassin's sympathetic account of Mbeki's actions placed him at the pinnacle of ‘an economy of suspicion and resentment’, implying that Mbeki was merely the most visible, powerful example of any (black African) man you might meet in the towns, cities or rural areas of South Africa. Jonny Steinberg's *Three Letter Plague* similarly links Mbeki's challenge to the global message to the opinions of locals: “[t]he accusations expressed in national politics are also stitched into village life, and indeed, into individual consciousness”.<sup>297</sup> In *A Different Kind of AIDS* (2014), the sociologist David Dickinson has however rebutted these conclusions, writing that “[t]o argue that people believed Mbeki, rather than public health messages, is easy, but wrong”.<sup>298</sup> Indeed, Dickinson indicates that the attention paid to Mbeki by scholars documenting the epidemic and its related political events itself reflects an epistemic bias towards power, and this attentiveness shields “the failure of social science to dig deeply into the reasons why behaviours have changed so

<sup>296</sup> Thabo Mbeki, ‘Speech by Thabo Mbeki at the Thirteenth International AIDS Conference, July 9, 2000’, in *Africa and the West: a Documentary History: Volume 2: From Colonialism to Independence* ed. by William H. Worger, Nancy L. Clark and Edward A. Alpers (Oxford: Oxford University Press), p. 234.

<sup>297</sup> Jonny Steinberg, *Three Letter Plague: A Young Man's Journey Through a Great Epidemic*, London, Vintage, 2009), p 8.

<sup>298</sup> David Dickinson, *A Different Kind of AIDS* (2014), p. 290

slowly” in which the actual “beliefs of the population have remained an intellectual afterthought”:

As [Mbeki] made his stand on AIDS, he neither reflected nor engaged with popular beliefs [such as those grounded in paradigms drawn from traditional medicines and religion]. Rather, the Great AIDS Debate was a dispute between elite groups.<sup>299</sup>

Whether the debate is between the Mbeki versus the TAC, or dissidents versus the medical community, both sides still represent to Dickinson the *public* transcript on AIDS. The conflict takes place within the epistemic “medical-human rights” framework of that transcript, in the haggling over ‘whether HIV causes AIDS’, for example. However, in the townships where Dickinson works, entirely separate paradigms of AIDS circulate, incorporating local concerns and urgencies, and the arguments of the powerful garner less interest. This is arguably where the similarity between Mbeki and ordinary citizens truly lies: the HIV/AIDS recommendations, focused on treatment access, were imposed with a fervour that “lost sight of people’s ability to think for themselves”,<sup>300</sup> that is, in both cases the humanitarian goal was thwarted by a failure to address epistemic injustices. He argues that these alternative or lay beliefs have never been taken seriously by researchers as knowledge, and therefore as public health professionals or humanitarians:

[W]e have lazily gone along with the view that the epidemic is driven by insufficient information and we have gone along with the assumption that people are ‘empty vessels’ into which the correct information can be deposited [...] In doing so, we have failed to understand why HIV/AIDS health promotion has been so ineffective.<sup>301</sup>

<sup>299</sup> Ibid, p. 288.

<sup>300</sup> Ibid, p. 290.

<sup>301</sup> David Dickinson, *A Different Kind of AIDS* (2014), pp. 290-303.

## **‘Blood on the Page’ or ‘An Eerie Silence’?**

One cultural sphere to which many researchers have turned in the hope of uncovering ordinary, ‘non-elite’ voices and experiences of HIV/AIDS is literature. Fiction and memoir writing is often seen as a way to counter dehumanising statistics and to even out epistemic injustice by giving people an avenue to “speak about HIV/AIDS in their own words, and on their own terms”.<sup>302</sup> However, in the South African context, silence once again is seen to figure prominently. While Steinberg’s diagnosis of an ‘eerie silence’ in South Africa takes as its starting point the political intellectual climate, the main emphasis of his essay is on the charting of a specifically *literary* silence. He recalls how, at the outset of researching the book that would become *Three Letter Plague* (2007), he was taken aback to discover his country had failed to produce discourse about - and in particular, “imaginative and intimate literature on AIDS”:

Mounds and mounds of words had been written on AIDS, of course, but there was little creative or personal writing about it. I found this quite shocking [...] reading through South African literary offerings, one would not have known that a flood of young deaths was washing through the land.<sup>303</sup>

The perceived lack of a defining AIDS work of literature for the African continent and diaspora is a refrain that exists at a key intersection for this thesis: that between narrative and

<sup>302</sup> Lizzy Attree, ‘Blood on the Page’ (2010), p. 20.

<sup>303</sup> Jonny Steinberg, ‘An Eerie Silence’ (2011), no pagination.



epidemic, and which is related to both local and universal debates around literature, social responsibility and representation.<sup>304</sup>

In Europe and North America, Steinberg pointed out, the outbreak of HIV/AIDS had prompted an outpouring of published narratives. These cultural interventions, conceived in an environment of ‘silence’ from national leadership, were often directly reacting to that indifference, and motivated by speaking back to sensationalised representations of homosexual people and other ‘risk groups’ (see: Attree, 2010; Kalinga, 2014).<sup>305</sup> Literature and visual art became key players in the battle over representations of the marginalised people who were most affected by HIV/AIDS, so that they now seem almost synonymous with evidence of efforts by affected communities to generate understanding and hope. Steinberg’s contrast therefore reflects negatively on the lack of a similar phenomenon in his country: “In the West, AIDS memoirs had long ago become a genre in their own right: in South Africa, it was as if the country and its writers had instead decided to change the subject”.<sup>306</sup> Despite the sub-Saharan region’s even more devastating statistics, the expected phenomenon of ‘speaking out’ through personal or imaginative literature did not occur on the same scale. Yet, this section suggests, the outpouring of AIDS memoirs was itself a kind of cultural anomaly, and by no means an archetypal response.

<sup>304</sup> In the Spanish flu context, Laura Spinney writes that “[t]he silence that is perhaps the most puzzling is the literary one” asking why the young American writers who lived through and were personally affected by the epidemic, including Ernest Hemingway, F. Scott Fitzgerald, and William Dos Passos, seemed to ignore the disease. The example of Spanish flu thus offers an interesting parallel example of how socially urgent issues do not axiomatically come to the forefront of the cultural or literary consciousness (Spinney, 2017, p. 262).

<sup>305</sup> Lizzy Attree, *Blood on the Page* (2010); Chisomo Kalinga, ‘The Responsibility of Memorialising Sex, The sDying and the Dead in HIV/AIDS Drama: Larry Kramer’s *The Normal Heart* and William Hoffman’s *As Is*’, (2014) <<http://www.stetjournal.org/memory/kalinga/>> [Accessed 7<sup>th</sup> September 2018]

<sup>306</sup> Jonny Steinberg, ‘An Eerie Silence’ (2011), no pagination.

The proliferation of Western AIDS memoirs occurred in the context of the general increase in academic and commercial interest in personal narratives, particularly of illness (c.f. Broyard 1993, Frank 1997 and Wiltshire 2000), during the second half of the twentieth century. The epidemic itself contributed greatly to the genre's increased visibility and legitimacy. Solipsistic accounts of coming to terms with suffering are now culturally normalized in this Global North context, but as recently as the 1960s, "medical sociology had [...] no category for the experience of being ill"<sup>307</sup> and Neil Vickers records that "book-length accounts of illness [...] were extremely rare before 1990".<sup>308</sup> Illness narratives gained traction partly as a retaliation to the increased medicalisation of the body in Western biomedicine, whereby the patient is constructed in primarily pathological terms (e.g. Kleinman, 1988). They have been valued as an avenue for re-humanising the sufferer by allowing them to 'reclaim' their sense of ownership over the body through narrative and redressing the epistemic imbalance inherent in the doctor-patient relationship. In this localised context, writing and literary expression can be seen as providing an outlet for catharsis and alternative self-conceptualisation.<sup>309</sup>

It is also important to appreciate that 'writing back' to discourses that marginalised and stigmatised PLWHA was a different task in the West. There, HIV/AIDS affected smaller groups, both in demographic terms and in relation to the general population (HIV prevalence in the United States never rose above 1%). Representing PLWHA in South Africa is a far more unwieldy and problematic task. As a large and extremely heterogeneous country, with huge divergences in income, living standards, and enormous diversity of cultural tradition,

<sup>307</sup> Arthur Frank, *The Wounded Storyteller* (2013), p. 15.

<sup>308</sup> Neil Vickers, 'Illness Narratives' (2016), p. 388.

<sup>309</sup> Particularly in the United States, they also notably "went hand in hand with advocacy of alternative therapies" (Neil Vickers, 'Illness Narrative' (2016) p. 388).

spiritual practice and language, there is no typical South African experience of HIV/AIDS. While literature can be an exponentially powerful factor in promoting social change, the spotlight on narrative representation as part of the toolkit against HIV/AIDS is drawn from the Western experience, one which accordingly produced “policies [that] were firmly voluntaristic and sensitive to the rights of the individual patient”,<sup>310</sup> a policy emphasis arguably that was inapt for a mass heterosexual epidemic. John Iliffe argues that “no Western government faced with an epidemic on the African scale would have dreamed of maintaining such a policy”,<sup>311</sup> that is, one so built on individual protection and behaviour change.

Perhaps significantly, the indigenous medical systems in South Africa (and several other non-Western societies) do not subscribe to the ‘Western’ allopathic view of a sick person through an impersonal, individualised optic. A process of narrating the experience of illness and the sense-making involved is integral, as Walker et al explain: “Traditional healers usually take a holistic approach, dealing with all aspects of the patient’s life, social context and psychological state [...] They also provide a conceptual framework that helps many of their patients to understand their illnesses”.<sup>312</sup> The late Phaswane Mpe, author of *Welcome to our Hillbrow* (2001) - one of the first South African novels to be internationally acknowledged and praised for its explicit treatment of HIV/AIDS – was training to become a healer before his untimely death. In an interview, he appeared to draw out some of the ways in which healers fulfil similar societal functions to novelists when he observed that:

<sup>310</sup> John Iliffe, *The African AIDS Epidemic* (2006), p. 65.

<sup>311</sup> Ibid, p. 69.

<sup>312</sup> Liz Walker, Graeme Reid and Morna Cornell, *Waiting to Happen: HIV/AIDS in South Africa – The Bigger Picture* (Boulder: Lynne Rienner Publishers, 2004), p. 94. My aim here is not to draw an oppositional binary between the health-seeking practice of South Africans and ‘Westerners’. Indigenous medicine systems in South Africa are widespread but also varied and hybridized. The hypothesis is that where there is a collaborative relationship between patient/sick person and medical practitioner in producing a diagnosis, there is perhaps less of the psychological compression that inspires the unspoken to find an outlet in the literary sphere.

Beyond using herbs, [traditional healers] are also interested in stories. Because when people come to you and say, “I’ve got a problem”, you don’t just say, “Well, is it a headache? Here is medicine for your headache”. You also want to know how they are doing in their social relationships, because perhaps the headache might come from elsewhere, from a source other than a germ or a virus. So you really have to be interested in stories...<sup>313</sup>

Stories, like illnesses, can be seen as embedded in a social and epistemological universe. In the essay ‘Affect and Narrative’, David S. Miall notes that when engaging with literary fiction, it is likely that “readers will draw on their normal modes of understanding people and encoding social episodes when reading stories”.<sup>314</sup> This evokes the issue introduced in the first chapter of the gap between the negative image and social reality, bridged with help of our imaginations and the archive socially available to us. Literature is popularly believed to be, as Zoe Norridge argues, “uniquely placed to represent pain because [it] excel[s] in the creation of new systems of meaning – vocabularies, grammars and image libraries of emotion – which render intelligible multifaceted and deeply personal beliefs and sensations”.<sup>315</sup> If the search for a Great AIDS Novel to emerge from South Africa derives from the idea that it is literature’s role to give suffering a human face, this search may need to be qualified with the consideration of ways in which existing systems – which act as the reader’s “normal modes of understanding people and encoding social episodes” - tend to be de-humanising and stigmatising.

<sup>313</sup> Lizzy Attree, *Blood on the Page* (2010), pp. 29-30.

<sup>314</sup> David S. Miall, ‘Affect and Narrative: A Model of Response to Stories’, *Poetics*, 17(3), (1988), pp. 259-260.

<sup>315</sup> Zoe Norridge, *Perceiving Pain in African Literature* (Hampshire: Palgrave Macmillan, 2013), p. 24.

Prior to Steinberg's article, several publications had in fact already been conceived in response to the perceived discursive void, including the book *Blood on the Page* (2010), quoted at the start of this chapter. Lizzy Attree's book is a collection of transcribed interviews with fourteen writers, from South Africa and Zimbabwe, who were writing about the epidemic in fiction or non-fiction.<sup>316</sup> Her book locates the source of the silence with those in power, contrasting the writers as producing "valuable and rare texts at a time when their governments were doing very little".<sup>317</sup> The writers who spoke with Attree include Phaswane Mpe, Jonny Steinberg, Liz McGregor, Niq Mhlongo and Siphiwo Mahala. A few years previously, in 2004, the anthology *Nobody Ever Said AIDS* was commissioned with funding from the Swedish International Development Cooperation Agency (SIDA). It is comprised of stories and poems from both established voices (including Achmat Dangor, Phaswane Mpe, Antjie Krog and a foreword by Njabulo Ndebele) and new or amateur writers. While both texts are literary in *theme*, they are essentially documentary in essence: largely fired by a motivation to highlight the humanitarian urgency of the epidemic, and to counteract "the over-reliance on statistics to tell the story of HIV/AIDS".<sup>318</sup>

Yet their common evaluation of the nature of the silence described unwittingly entrenches a tendency to problematize the country.<sup>319</sup> Both collections therefore represent an interesting

<sup>316</sup> Attree is currently the administrator of the Caine Prize, an international literary prize for writing in English from the African continent.

<sup>317</sup> Lizzy Attree, *Blood on the Page* (2010), p. 5.

<sup>318</sup> Ibid, p. 3.

<sup>319</sup> The writers are not unaware of this: In interview with Attree, Steinberg rebukes the British writer for looking for "this authentic, black voice on AIDS out there, the real unmediated experience of the epidemic [which] no one has written down yet" (Lizzy Attree, *Blood on the Page* (2010), p. 167). Meanwhile during an earlier conversation with the poet Kgafela Oa Magogodi, Attree herself grapples with the ambivalent effects of the project, expressing the concern that it might be "reductive to look, the way I am, which is kind of hard to stop now, because I've got to finish, but to go for subject matter, like AIDS and to then look across different literary forms" (p. 94).

encounter between the international public transcript on HIV/AIDS, which sees South Africans as unreflective or unreactive about the scale of disaster in their midst, and the transcripts that are hidden from view. For example, the anthology *Nobody Ever Said AIDS* (2004) takes its title after a poem written by Eddie Valuni Maluleke, which is also placed at the beginning of the collection, an act of curation which itself can be seen as one way in which silence is reiterated in the construction of African discourse. In the title poem of the HIV/AIDS anthology, Maluleke depicts a funeral where the deceased person's family and friends mourn without ever naming the cause of death. The Swedish editors' decision to foreground this poem highlights taboo and silence as the paramount issue around AIDS, as well as characterising the contents of the rest of the volume.

Anthony O'Brien has explained that the literary critic and author Njabulo Ndebele – who provided the foreword to the Swedish anthology - had an “activist approach to white reception of black texts [which] stressed the need to ‘alter perceptions’, not confirm them”.<sup>320</sup> Titles were important to Ndebele on account of their being the first point of encounter for the reader, and thus their ability to shape the reception of the text within. O'Brien relates how, in 1971, the poet Oswald Mbuysei Mtshali published a volume of poetry titled *Sounds of a Cowhide Drum* which would prove groundbreaking in the country<sup>321</sup>. The collection was received with pride and excitement, including a praise-filled foreword by Nadine Gordimer. However, in Ndebele's undergraduate thesis (later published as ‘Artistic and Political Mirage: Mtshali's *Sounds of a Cowhide Drum*’) he critiqued the title's imagery as “salutary rather for

<sup>320</sup> Anthony O'Brien, *Against Normalisation: Writing Radical Democracy in South Africa* (Durham: Duke University Press, 2001). p.48

<sup>321</sup> Mtshali's collection “broke a decade of silence imposed by censorship, jail and exile; it was the first volume of poetry ever to make a profit in South Africa and went through five printings in two years (Barnett 34)”, cited in Anthony O'Brien, *Against Normalisation: Writing Radical Democracy in South Africa* (Durham: Duke University Press, 2001), p. 44.

white readers at a certain point, not for black, and therefore as only ‘one part of the artistic problem’ which the black South African writer has to confront’:<sup>322</sup>

Mtshali called his book *Sounds of a Cowhide Drum*. Not bad. But it was taking an anthropological posture that I did not, and still do not believe in. The same goes for Serote’s *Yakhal’inkomo* (Cry of the Cattle) but in an urban setting [...] Then Serote came with *No Baby Must Weep*. After that, we cannot have any more titles which imply that people are still weeping.<sup>323</sup>

The humanitarian aim of the volumes, in other words, is in some part tempered by its reproduction of a stereotypical image of Africa, which in turn contributes to the kind of stereotype or identity-prejudicial threat that is key to the maintenance of epistemic injustice. If books merely confirm the existing impressions of the readers, Ndebele argued, the effect would be to “standardise reader response”, encouraging a type of passive sympathy rather than the active empathy that might have a “profound bearing on his own humanity”.<sup>324</sup> Knowing this perhaps contextualises Ndebele’s rather restrained foreword to the Swedish anthology within South African literary history. On another occasion, also described by Anthony O’Brien, he even threatened to withdraw his poems from an anthology of black poetry, remonstrating that its proposed title, *Ask Any Black Man*, re-centred the white gaze:

Who should ask any black man? Surely not another African ... it’s the white man who has to ask any black man. So we have yet another book appealing to the conscience of those who have been proven not to have any... The point of the matter is that the suggested title still very much makes Africans alien objects of interest.<sup>325</sup>

<sup>322</sup> Njabulo Ndebele cited in Anthony O’Brien, *Against Normalisation: Writing Radical Democracy in South Africa* (Durham: Duke University Press, 2001), p. 44.

<sup>323</sup> Ibid, p. 44.

<sup>324</sup> Ibid, p. 48.

<sup>325</sup> Ibid, p. 48.

In January 2003, the American novelist Norman Rush wrote a 4200-word review in the *New York Review of Books* of Zakes Mda's novels *The Heart of Redness* (2002) and *Ways of Dying* (1995) under the title 'Apocalypse When?', which found Mda guilty of "a great omission" (Rush, 2003, no pagination). The omission he discerned was that "[t]he AIDS pandemic is absent, totally absent, here [in these novels]. That's an impossibility".<sup>326</sup> Rush argued that Mda's failure to centralise HIV/AIDS in the world of the novels impacted "profoundly detrimentally" on the books' accomplishment. In a concerted effort to locate the absent epidemic, he muses that Mda's use of the Great Cattle Killing (an event that was pivotal in Xhosa history and identity) in the plot of *The Heart of Redness* might have been intended to stand in for HIV/AIDS, although this leads him to the conclusion that "[t]o conjecture that Mda might be using the Great Cattle Killing as an AIDS metaphor, you must propose that he is suggesting that AIDS is in actuality a good thing. It is not possible that he is doing that. I have no good explanation".<sup>327</sup>

Ndebele's objections are related to what Henry Louis Gates Jr has called the "anthropology fallacy" and Ainehi Edoro "the anthropological unconscious of the African novel".<sup>328</sup> These terms refer to the practice of reading African literary fiction as documentary information about the area's customs and social issues, rather than in terms of its aesthetic achievements.

<sup>326</sup> Norman Rush, 'Apocalypse When?' <<https://www.nybooks.com/articles/2003/01/16/apocalypse-when/>>, [Accessed 29<sup>th</sup> August 2018]. Rather astonishingly, this apparently exhaustive critique ends with Rush telling the reader "I don't know a great deal about Zakes Mda [...] I'm not familiar with his plays, and it may be that he has addressed questions like mine in other aesthetic venues" (2003, no pagination). In response to Rush's review, Mda observed that J.M. Coetzee had not been subjected to the same criticism for his novel *Disgrace* (1999), which also fails to mention the topic.

<sup>327</sup> Ibid, no pagination.

<sup>328</sup> Henry Louis Gates Jr, *Black Literature and Literary Theory* (London: Routledge, 1984 (2016)), p. 5); Ainehi Edoro, 'How not to talk about African fiction' (2006), <<http://www.theguardian.com/books/2016/apr/06/how-not-to-talk-about-african-fiction/>>, [Accessed 29<sup>th</sup> August 2018]



Postcolonial theorists have contributed to dismantling the ways in which African literatures are shunted “into a space outside art and literary figuration and into sociological data”<sup>329</sup> and accordingly packaged for consumption in terms of its social or political themes and issues. Reading Rush’s critique itself through a postcolonial framework suggests “the imposition of a literary time-scale where African novels are assessed according to the traditions of late 19<sup>th</sup> century European realism”.<sup>330</sup> The inability to assess Mda’s novels outside of his own expectations for what the proper subject of South African literature in the early 2000s should be produces a strenuously convoluted argument, which ends in the implication that it is Mda’s writing itself which is unfathomable. Close to the article’s end, he concludes: “With AIDS omitted, Mda has created a novel that is, finally, an escapist dream, a fable more than a parable”.<sup>331</sup> This is the clearest statement that Mda’s turn of the 21<sup>st</sup> century works are in fact being judged against the standards of late 19<sup>th</sup> century European realism, despite no indication that this was Mda’s aesthetic intention. As Rush determines Mda’s novel falls short of these imposed standards, he demotes it from the status of novel to ‘a fable’, implying it is childlike, unliterary and unworthy of his proper attention.

Rush frames his omission-centred critical angle with a semi-flippant acknowledgement of postmodernist scholarly critiques laid against authors writing in that realist tradition:

Here’s a random sample of such lacunae: Jane Austen (plantation slavery), Joseph Conrad (race), a good part of the nineteenth-century pantheon of American writers (slavery, race), George Eliot (deficiencies in women’s educational access)...<sup>332</sup>

<sup>329</sup> Kadiatu Kanneh, ‘What is African literature?: ethnography and criticism’, in *Writing and Africa*, ed. by Mpalive-Hangson Msiska and Paul Hyland (Harlow: Longman, 1997), p. 73.

<sup>330</sup> Ibid, p. 75.

<sup>331</sup> Norman Rush, ‘Apocalypse When?’ (2003), no pagination.

<sup>332</sup> Norman Rush, ‘Apocalypse When?’ (2003), no pagination.

This list requires unpacking. Although there has been serious literary criticism of this nature produced about the works of Austen, Conrad and Eliot, it is surely a stretch to state, as Rush does, that these authors have now “*become* [their] omissions”.<sup>333</sup> In addition, with regards to perhaps the most prominent of those critiques, Conrad does not leave out race from *Heart of Darkness*, but in fact builds the fundamental assumptions of white supremacy into its structure and linguistic world. Equally, black Africans are not ‘totally absent’ from the novella; rather - and much worse - they are portrayed but dehumanised as peripheral, indistinct masses. Conrad’s omission is not race, but reality. The primary aim of postcolonial, feminist and other revisionist theoretical critiques of canonical literary works is not to vindictively single out ‘authorial shortcomings’ but to demonstrate how the lacunae produced by patriarchal and imperial ideologies, converged with these texts, to sculpt and exert hegemonic force over our worldviews.<sup>334</sup> If these theorists seek to dismantle enduring harmful power dynamics in order to “salvag[e] futures scarred by imperial greed”,<sup>335</sup> then Rush’s attempt to place his review of a contemporaneous African author in the same lineage surely jars.

The expectations identified that the South African literary response to HIV/AIDS should parallel that of the West can be related to what Bagele Chilisa calls “the error of sameness or universalism”.<sup>336</sup> She writes elsewhere in the article that even though local contextual

<sup>333</sup> Ibid, my emphasis.

<sup>334</sup> For example, in Nancy Armstrong suggests that the novel played a part in producing the cultural apparatus that regulate ‘bad subjects’ (qua Althusser), including those who contradicted the Enlightenment ideal individual. As colonialism and the global trade of objects made it difficult to maintain a sense of British identity based in birthplace, fiction invested desire in “the imaginary nation”. Nancy Armstrong, *How Novels Think* (Place: Publisher, 2005), p. 63).

<sup>335</sup> Grace Musila, ‘Chimamanda Adichie: The daughter of postcolonial theory’ (2018), <<https://www.aljazeera.com/indepth/opinion/chimamanda-adichie-burden-representation-180204094739657.html>>, [Accessed 29<sup>th</sup> August 2018]

<sup>336</sup> Bagele Chilisa, ‘Educational research within postcolonial Africa’, p. 672.

information has become more valued, it is still often “limited to those factors that can be contrasted with standard First World experiences”.<sup>337</sup> The comparison conveys the historicist “first in the West, then elsewhere” notion that implies there is only one path to progress.<sup>338</sup> In this narrative, the West is discursively constructed the singular origin of AIDS healing (even as Africa is correspondingly made the singular origin of disease). To put it another way, the syllogism goes that the West has tamed the spread of the AIDS epidemic within its borders; the West produced a great deal of AIDS writing; and therefore, if South Africans were really serious about tackling the epidemic they ought to produce more (or better) writing.<sup>339</sup> While assuming ‘sameness’ of response is clearly erroneous, the contrast nevertheless prompts us to consider the conditions in which narrative-making becomes a coherent and useful tool.

Heather Love notes that the “methodological continuity” whereby hermeneutic interpretation has inherited “the site of moral education and self-making” from religious scholarship produced a belief in the “ethical force of literature”.<sup>340</sup> This underlying foundation contributes to a relatively widespread consensus that “[l]iterary intellectuals play a vital part in [the] process of ideological critique and utopian revision of the normal”,<sup>341</sup> and the sense of prestige and legitimacy with which the authorial voice has been endowed naturally has ramifications in the context of social crises, such as the anti-Apartheid struggle and the HIV/AIDS epidemic.

<sup>337</sup> Ibid, p. 672.

<sup>338</sup> Dipesh Chakraborty, *Provincialising Europe: Postcolonial Thought and Historical Difference* (New Jersey: Princeton University Press, 2000), p. 6.

<sup>339</sup> Claire Hooker and Estelle Noonan have suggested that, despite “the excellent intentions of its founders and practitioners, medical humanities as a field has often been strongly, though not whole, reflective of the traditions of Western (Anglo-American and European) culture, particularly what used to be referred to as ‘high’ culture” (Claire Hooker and Estelle Noonan, ‘Medical Humanities as Expressive of Western Culture’, *Medical Humanities*, 37(2), (2011), 79-84. doi: 10.1136/medhum-20110010120)

<sup>340</sup> Heather Love, ‘Close but not Deep: Literary Ethics and the Descriptive Turn’, *New Literary History*, 41, (2010), p. 373; p. 371.

<sup>341</sup> Anthony O Brian, *Against Normalization* (2001), p. 4.

Assuming contemporary South African writers want to tackle social issues, it might be more accurate to say not that writers are changing the subject from AIDS, but that AIDS is one subject among many. This is unsurprising when taking in the surfeit of concerns facing a writer and citizen of the newly democratic, desegregated society, only a few years after a prolonged civil war. *Welcome to Our Hillbrow* features several characters who live with and die from AIDS and is largely assumed to draw from the author's own experiences.<sup>342</sup>

Nevertheless, as the linguist Vicki Briault-Manus points out, HIV/AIDS is only one of a host of "important matters which are deliberately foregrounded and thoroughly discussed [including] love, friendship, homosexuality, getting drunk, death, suicide, AIDS, xenophobia, witchcraft...".<sup>343</sup> As the sub-title 'A Novel of Post-Apartheid South Africa' suggests, a focus on any single issue depicted in his forcefully poetic novel would have failed to capture the full texture of reality. In an interview with Liz McGregor, Mpe stated that:

My vision is to contribute to a critical engagement with, and artistically sound contribution to, reflections on sensitive issues in South African literature and society. This is important for the sake of fighting against complacency, as well as providing an antidote to those who think that South Africans have nothing to write about in the post-Apartheid context".<sup>344</sup>

His words disclose not only that the novel is intended as direct and explicit engagement and representation of the epidemic, but also how writers in post-Apartheid South Africa felt several, overlapping discursive pressures. Far from rejecting a call to write about HIV/AIDS,

<sup>342</sup> Mpe died aged 34 in 2004, and it has been inferred by many commentators that his death was from AIDS-related causes. This may be true although *Welcome to Our Hillbrow* and other interviews or stories testify to Mpe's long-term depression and suicidality, from which writing offered a rare respite.

<sup>343</sup> Vicki Briault-Manus, *Emerging Traditions: Towards a Postcolonial Stylistics of Black South African Fiction in English* (Plymouth: Lexington Books, 2011), p. 238.

<sup>344</sup> Lizzy Attree, 'Interview with Phaswane Mpe', in *Words Gone Too Soon: A Tribute to Phaswane Mpe and K. Sello Duiker*, ed. Mbulelo ViziKhungo Mzamane (Pretoria: Umgangatho Media, 2005), p. 42.

Mpe's novel aimed to overcome expectations that the injustices perpetrated by Apartheid were the true subject for literature at the time.

In addition, a direct comparison between Western and African HIV/AIDS narratives also belies, in its invoking of an idealised reading audience, the marked material differences between the cultural outlet of publishing one's story in the two places. In South Africa, the reading and book-buying market is still developing and so is currently far less sizeable or lucrative. Recent industry figures show that only 75,000 copies of local novels written in English were sold in the whole country in 2015, and an oft-quoted statistic in local literary spheres is that a novel is deemed a success if it sells 1,000 copies in the author's lifetime.<sup>345</sup> The cultural imagination of the centre continues to hold a hegemonic sway over book sales and reading habits. Moreover, the legacy of Apartheid social engineering – which forbade swathes of non-white cultural activity - continues to influence the literary infrastructure, with the white minority consistently over-represented in both publishing and published works.<sup>346</sup> South African AIDS memoirs such as Justice Edwin Cameron's *Witness to AIDS* (2005), and non-fiction works including Liz McGregor's *Khabzela!* (2006) and Steinberg's *Three Letter Plague* (2007) are described by Steinberg in his essay as white writers "trying to interpret

<sup>345</sup> BusinessTech, 'The shocking number of books an average South African author sells', <<https://businesstech.co.za/news/general/134230/the-shocking-number-of-books-the-average-south-african-author-sells>> [Accessed 7<sup>th</sup> September 2018]

<sup>346</sup> A number of recent literary events illustrate how authors are grappling with problems relating to unequal access in South Africa and attempting to change this status quo. In 2015, the novelist Thando Mgqolozana declared his intention to boycott South African literary festivals, citing a fatigue with an infrastructure that "systematically excludes black people" (Jennifer Platt, "'Look at Yourselves – It's Very Abnormal': Thando Mgqolozana Quits South Africa's 'White Literary System'", <<http://bookslive.co.za/blog/2015/05/18/look-at-yourselves-its-very-abnormal-thando-mgqolozana-quits-south-africas-white-literary-system/>> [Accessed 1<sup>st</sup> September 2018]). He has since established his own Abantu Book Festival which is held annually in the Soweto township. Meanwhile, in 2017, the political commentator and activist Sizwe Mpofu-Walsh published his book of essays *Democracy and Delusion* with a companion hip-hop album, each song corresponding to a chapter in the book. He explained to an interviewer that he wanted to "use different methods to get [his] messages across" (Govan Whittles, 'Literary bent to hip-hop's Democracy & Delusion', <<https://mg.co.za/article/2017-08-18-00-literary-bent-to-hip-hops-democracy-delusion/>> [Accessed 1<sup>st</sup> September 2018]).

black people's experiences of AIDS".<sup>347</sup> This however speaks to demographic disparity in ease of access to agents and publishers, and not only to different groups' will or inclination to interpret experience. Simply put, literary production is not a power-neutral pursuit.<sup>348</sup> As the novelist and professor of creative writing Imraan Coovadia has lamented, the pressures faced by writers are not only discursive or political but also material:

South Africa is not a country conducive to serious writing. I don't mean serious in the sense of solemn, but serious in the sense of someone taking two to five years out of life to write.

The economics aren't there, the readership isn't there and the career structure isn't there.<sup>349</sup>

In spite of these obstacles, a number of novelists have engaged with the epidemic, albeit in some cases obliquely. In his essay, the works that Steinberg singles out and praises for their "raw and private" subject matter and exploration of "intimate territory" are: Thando Mqolozana's *A Man Who Is Not A Man* (2009); Siphiwo Mahala's *When A Man Cries* (2007); and Niq Mhlongo's *Dog Eat Dog* (2004) and *After Tears* (2007).<sup>350</sup> As the titles suggest, these works indeed share a concern with the contradictions of manifesting viable performances of masculinity at a time of social recalibrations of power. Mqolozana's

<sup>347</sup> Jonny Steinberg, 'An Eerie Silence' (2011), no pagination.

<sup>348</sup> This potential disconnect between the assumptions made about literary power to exercise social impact and the reality of readership in South Africa is indeed made obvious in *Three Letter Plague*. When explaining to the man who becomes the book's protagonist the need for a pseudonym in order to protect his anonymity after publication, Steinberg recalls that "[s]ometimes he seemed to take this advice to heart, but mostly he could not take it seriously at all. In all his years, he had seldom seen anyone in Ithanga reading a book, nor [...] had he ever heard a single conversation about one" (2009, p. 350).

<sup>349</sup> Imraan Coovadia, 'Imraan Coovadia on South African Fiction' <<https://fivebooks.com/best-books/imraan-coovadia-on-south-african-fiction/>> [Accessed 29<sup>th</sup> August 2018]

<sup>350</sup> Strangely not included in this list is K. Sello Duiker's *The Quiet Violence of Dreams* (2001), a visceral bildungsroman now regarded as a classic, which includes themes such as mental illness and institutionalisation, gang violence, rape and sex work. Given that a large part of the novel is set in a sex parlour called Steamy Windows and in queer bars and spaces, it is also surprising that Duiker's novel has received little criticism for its characters' apparent lack of awareness about AIDS. Mpe, Duiker and Mda were often linked as the new literary stars of the post-Apartheid generation of black writers.

character questions the validity of his dutifulness to the Xhosa initiation rite, when he lacks a familial male figure who would guide him into manhood. In absence of a responsible adult caretaker, he returns from the mountains a ‘failed man’, although his novel questions this cultural authority to determine his social status in a way that arguably only became possible (although still controversial) in the aftermath of Apartheid’s collapse. In Mhlongo’s *After Tears*, the protagonist returns to Johannesburg having dropped out of law school but hides this fact from his family. Under the impression that he now is an advocate, the community seeks to benefit from his new social status. In both, there is a probing of the boundaries of power and authority, and an awareness of the post-Apartheid moment as a moment in which their meanings were particularly malleable, mercurial and open to manipulation – for better and worse.

At the same time, another motif that connects many of the new crop of novels was precisely the existence of obstacles to writers’ authentic expression. *Welcome to Our Hillbrow* (2001) in particular exhibits an ambivalence towards the state of literary production and reception in South Africa. The novel opens by elegiacally addressing in the second person his character Refentse, who by the beginning of the novel will have already taken his own life. Like Refentse, Mpe was a lecturer at the University of the Witwatersrand in Johannesburg, and he struggled with depression and suicidal thoughts before his death in 2004. *Welcome to Our Hillbrow* was begun as a “therapeutic engagement” during a period of depression in 1999, “to reassure [himself] that [his] life was worth living”.<sup>351</sup> Refentse is also a writer who has begun writing a short story about Hillbrow in an effort to assuage his feelings relating to a friend’s death in a fatal accident. These biographical overlaps create an effect where the second

<sup>351</sup> Lizzy Attree, ‘Interview with Phaswane Mpe’ (2005), p.42.

person narration seems to flicker between Mpe writing as much to himself – reassuringly - as to his character:

You wrote your story in order to find sanctuary in the worlds of fiction that are never quite what we label them. You wrote it in order to steady yourself against grief and prejudice, against the painful and complex realities of humanness.<sup>352</sup>

An additional stratum in this metafictional layering is produced as the heroine of Refentse's short story about Hillbrow in turn begins writing in order to find a means of expression:

But as you started writing it, it turned into something else. It became instead a story about an HIV-positive woman from Tiragalong, who was ostracised by her fellow villagers when they learned about her health status [...] her second resolution was to pour all her grief and alienation into the world of storytelling. You had her write a novel about Hillbrow, xenophobia and AIDS and the prejudices of rural lives.<sup>353</sup>

Even in the fictional world within Mpe's fiction, however, expression is limited by the unbendingness of testimonial injustice. The honesty of Refentse's writer, and her desire to write in Sepedi, prevents her manuscript from reaching an audience: "She did not know that writing in a South African language in South Africa could be such a curse".<sup>354</sup> Mpe's fictional character's fictional character comes up against the very real obstacles of a book-selling industry marked by Apartheid censorship and indoctrination, which he implies has been internalised so that even in 1995, "despite the so-called new dispensation, nothing had really changed [...] Publishers, scared of being found on the financially dangerous side of the censorship border, still rejected manuscripts that too realistically called things by their proper

<sup>352</sup> Phaswane Mpe, *Welcome to Our Hillbrow* (Scottsville: University of Natal Press 2001), p. 59.

<sup>353</sup> Ibid, p. 55.

<sup>354</sup> Phaswane Mpe, *Welcome to Our Hillbrow* (2001), p. 56.



names”.<sup>355</sup> As a result, the story “remained buried in the heroine’s files”.<sup>356</sup> While both Refentse’s heroine and Refentse (Mpe’s hero) represent a foil to Mpe’s actual publishing and critical success, they also record his frustrating experiences as a South African writer. Mpe seems to remind the reader that his novel reaches them against the odds, and of the many other important stories buried by a discouraging system. Later, the narrator shifts his focus to the story of Refentse’s former girlfriend, Refilwe, who gains a job as Commissioning Editor at a prestigious publishing company. At first excited by the challenges of her new role, she soon becomes downcast at its limits:

Although she knew what good books looked like, the company kept reminding her that good books were only those that could get a school prescription. What frustrated her so much was the extent to which publishing was in many ways out of touch with the language and events of everyday life.<sup>357</sup>

The effect of Mpe’s and his characters’ struggles to fully articulate their internal conflicts, in the face of regressive public opinion, is to intimate what inexorably remains unspoken.

Adrian Knapp writes that *Welcome to Our Hillbrow* “works against its own claims of representing the (absolute) truth by commenting on the selective and incomplete quality of the story”.<sup>358</sup> The novel’s self-referentiality towards its own creation is not only a stylistic device, however. It also emphasises that an element of the post-Apartheid reality which it seeks to reflect is precisely the concealment from written culture, the spoken language that “people of Tiragolong and Hillbrow and everywhere in the world used every day”.<sup>359</sup> The

<sup>355</sup> Ibid, p. 57.

<sup>356</sup> Ibid, p. 58.

<sup>357</sup> Ibid, p. 94.

<sup>358</sup> Adrian Knapp, *The Past Coming to Roost in the Present: Historicising History in Four Post-Apartheid South African Novels* (Stuttgart and Hanover: Ibidem Press, 2006), p. 92.

<sup>359</sup> Phaswane Mpe, *Welcome to Our Hillbrow* (2001), p. 57.

question of sociality therefore again becomes fundamental to characterisations of South African literary silence on HIV/AIDS, which pivots on whether black writers have a particular responsibility to depict the experience of the epidemic in a way which is both aesthetically permissible, and epistemologically intelligible to outsiders.<sup>360</sup>

## Conclusion

In his introduction to Njabulo Ndebele's *Rediscovery of the Ordinary*, Graham Pechey glosses that "Ndebele is careful to insist on the peculiar authority of the written word (its very 'intimate' invasion of consciousness) and on the need for the oppressed to claim that authority for themselves, but not before they have broadened its scope by articulating in writing the whole range of their experience".<sup>361</sup> The appeal that Pechey draws out is that literature produced from the 'margins' must not centralise the gaze of the 'centre', one reason being that the centre is unlikely to be able to imagine with any granularity the 'hidden transcript' beyond its own reality. Thus the formerly oppressed cannot reclaim language by deploying it for the purposes of the centre's imagination, but need to defy its mythologising effects. This chapter's discussion of silences, real and perceived, reveal a convergence between the disciplines of literary criticism and social studies in terms of a need for widened epistemological vantage points. Different ways of reading are still required in order to do justice to writing and expression in the postcolony, just as James Scott noted that traditional ways of doing social studies may end up recording only the dominated communities'

<sup>360</sup> As the poet Kgafela Oa Magogodi vividly puts it to Lizzy Attree in an interview for *Blood on the Page*: Zakes Mda observes how, recently, the *Sunday Times* had a picnic at the Cape Town Book Fair entertaining a gullible liberal audience with silly questions about why there are no new black writers. This is assuming that Phaswane Mpe and Sello Duiker never tasted life. Maybe Zebulon Dread is wasting time publishing obscene prose with overdose of anger against white society – he will never find space in the shelves of Exclusive Books. [They want] a bongo-bongo poet with a Tarzanic vision of the continent. [...] some of us refused the incarcerating patronage of liberal dinosaurs and now they want us erased. But this is not just a literary problem" (Lizzy Attree, *Blood on the Page* (2010), p. 78).

<sup>361</sup> Graham Pechey, 'Introduction', in Njabulo Ndebele, *South African Literature and Culture: rediscovery of the ordinary* (Manchester: Manchester University Press, 1994), p. 9.

perspective on the events or issues deemed important by the power-holders, rather than the full range of their lived experiences and views:

How do we study power relations when the powerless are often obliged to adopt a strategic pose in the presence of the powerful and when the powerful may have an interest in overdramatizing their reputation and mastery? If we take all this at face value we risk mistaking what may be a tactic for the whole story.<sup>362</sup>

It is for this reason that the thesis follows a multi-disciplinary approach, in an effort to evade – not always successfully – the intrinsic power imbalances of the existing discourses that have not been entirely successful in apprehending narratives or realities of HIV/AIDS. The transnational literary scholar Paul Jay writes that cultural studies provides “a context for studying literary texts and works in other media not simply as aesthetic objects but also as cultural objects caught up in complex systems of transnational and intercultural exchange, appropriation and transformation”,<sup>363</sup> a point which is borne out by the above discussion of the decisive material or logistical barriers which many South African writers need to overcome in order to reach readers in the first place. In reading how the epidemic has been represented, such an approach is relevant anywhere that could be considered the ‘margin’ or ‘peripheries’: as the American scholar Barbara Browning wrote in her contribution to the essay collection *AIDS – the literary response*: “I, too, am hoping in earnest of the pan-African text of the epidemic. [However] if the text is missing, the first question to ask is not

<sup>362</sup> James Scott, *Domination and the Arts of Resistance* (1990), p. xxi. Within literary studies, Franco Moretti argues that “[r]eading ‘more’ seems hardly the solution [...] the sheer enormity of the task makes it clear that world literature cannot be literature, bigger; what we are already doing, just more of it. It has to be different. The categories have to be different. [...] world literature is not an object, it’s a problem, and a problem that asks for a new critical method...” (Franco Moretti, ‘Conjectures on World Literature’ (2000), <<https://newleftreview.org/II/1/franco-moretti-conjectures-on-world-literature>> [Accessed 1<sup>st</sup> September 2018]).

<sup>363</sup> Paul Jay, ‘Beyond Discipline? Globalization and the Future of English’, *PMLA*, 116(1), (2001), p.44.

necessarily why wasn't it written? But if it has been written, will it be published, and will it be read?"<sup>364</sup>

Due to the hegemony of what Scott calls the 'public transcript', even when textual artefacts are produced without consciously referencing power or where they actively reject the terms of the conversation – it is impossible fully to escape this framework, because the dominant group is able to impose its understanding of the world on reality, with the result that abstract or virtual models can appear more legitimate and real than socially embedded, lived realities. I have suggested that 'silence' can be understood in this way, and that what is often reported as 'silence' is more complex and multivalent. The prevailing negative space has important ramifications on how texts that deal with HIV/AIDS are received, particularly if new knowledge is produced with reference to an incomplete and tendentious archive. Texts aiming to speak about HIV/AIDS, including the two novels discussed in the following chapter, materialise within this landscape and must reckon with the 'silences' which are discursively constructed through the de-legitimation or erasure of those knowledges. Focusing on how writers themselves narrate the conditions under which fiction was being produced in the post-apartheid moment invites us to re-appraise the dichotomy between silence and expression, and indeed to resist the temptation to understand emotional and aesthetic solidarities as necessarily precipitating changes of a material, economic and institutional nature.

<sup>364</sup> Barbara Browning, 'Babaluaiye: searching for the text of a pandemic' in *AIDS – the literary response*, ed. by Emmanuel S. Nelson (New York: Maxwell Macmillan International, 1992), p. 86.



## CHAPTER FOUR – HIV/AIDS AND THE POST-APARTHEID CONDITION IN TWO CONTEMPORARY NOVELS

[W]e must always contend with the fact that even under the most oppressive of conditions, people are always trying and struggling to maintain a semblance of normal social order... The transformation of those values constitutes the essential drama in the lives of ordinary people.

Njabulo Ndebele, *Rediscovery of the Ordinary* (1994)

The worst thing that can happen in this story, Cissie says, is that someone dies, and that's already kind of happened, hasn't it?

Masande Ntshanga, *The Reactive* (2014)<sup>365</sup>

Masande Ntshanga's striking and formally assured debut novel *The Reactive* was published in 2014, the same year as Imraan Coovadia's *Tales of the Metric System*. Interestingly, both of these authors choose to examine the South African HIV/AIDS story through fictionally rendering the period in which the treatment controversy was at its highest, that is the early 2000s. Similarly to the story 'Sparks (2000)', *The Reactive's* present-tense action takes place at the height of the 'AIDS denialism' era. Like Sparks, Ntshanga's protagonist Nathi is among the minority of South Africans who are fortunate enough to be able to access ART – in his case, through a private health plan paid for by a workplace insurance policy, after he was infected at the laboratory where he worked. However, even though Nathi is – unlike

<sup>365</sup> Njabulo Ndebele, *South African Literature and Culture: rediscovery of the ordinary* (Manchester: Manchester University Press, 1994), p. 55; Masande Ntshanga, *The Reactive* (London: Jacaranda Books, p. 83). Masande Ntshanga is an author from East London in the Eastern Cape, who won the PEN International New Voices Prize in 2013 with his short story, 'Space', which also treats the theme of HIV/AIDS in the new country.

Sparks - equipped with an understanding of the disease's transmission mechanisms ('AIDS literacy'), he rejects the salvation path of treatment and chooses instead to sell his medication on the black market to those without that option. Although far less overtly political than Coovadia, Ntshanga's addition of a quote from Thabo Mbeki ("The question we have to ask is, does HIV cause AIDS?") as an epigraph to the American edition explicitly links his novel to the political events in his country. Somewhat ironically, however, Nathi mirrors the former President in his initial rejection of the restitution narrative promised by anti-retroviral drugs.

The medical humanities scholars Claire Hooker and Estelle Noonan have noted a tendency within its canon to "naturalise certain features as part of the *experience* of illness and healing, instead of understanding these as *constructed* and expected features of a genre".<sup>366</sup> In contrast to where Arthur Frank writes that a fundamental element of illness narrative is that "[a]nyone who is sick wants to be healthy again",<sup>367</sup> Ntshanga's protagonist seems initially indifferent to the possibility of recovery, or at least managing his condition with treatment. The characters have given what Nathi predicts to be his "last year on the planet", the nickname of 'Last Life', and ask themselves how they ought to spend it:

What we're doing right now is having one of our talks about what to do for Last Life [...]

Like always, we stayed up for most of the previous night with the question. We finished the wine first. Then we moved on to the bottle of benzene.<sup>368</sup>

Apart from a reference to Nathi's body as "bone-thin",<sup>369</sup> we are not made privy to symptoms of illness that cannot be attributed to a hangover or a come-down. *The Reactive* itself seems to be less 'about' living with HIV than it is about living with guilt, with the ghosts of one's

<sup>366</sup> Claire Hooker and Estelle Noonan, 'Medical Humanities as Expressive of Western Culture' (2011), p. 7.

<sup>367</sup> Arthur Frank, *The Wounded Storyteller* (2013), p. 77.

<sup>368</sup> Ibid, p. 19.

<sup>369</sup> Masande Ntshanga, *The Reactive* (2014), p. 11.

past, with cultural expectations, with privilege and finally, about living with integrity and intention. The novel is not an illness narrative, therefore, but neither is it a disease narrative in the sense that I have suggested we might consider some of the texts described in the previous chapter. Nathi's studied removal of dread around his diagnosis presents an essentially anti-tragic view of the universe, if we see mortality as the hamartia shared by all human beings.<sup>370</sup> In this chapter I explore ways in which Ntshanga's narrative strategies create a novel that unseats our predictions, and contend that this in itself forms a radical cultural response to the epidemic, challenging and expanding our notions of an intrinsic affective experience of HIV/AIDS.

Portrayals of HIV/AIDS in Coovadia's novel, as discussed briefly in the second chapter, were concerned to link the existence and extent of the epidemic in South Africa to the contemporaneous political developments. In combination, the interest of both authors in the ART debate comes to shed light on both the processes of knowledge production in the country and the increasing neo-liberalisation of South Africa in the new post-Apartheid era. In depicting the concurrent advent of democratic freedom and HIV/AIDS to South Africa, two decades after the end of Apartheid, the two novels' engagement of Mbeki's policies may be seen as a sign of the shifting discursive environment regarding the post-democratic nation, reflecting a growing disillusionment with the ANC. As Achille Mbembe has argued, "a new cultural temperament is gradually engulfing post-Apartheid urban South Africa [and] the

<sup>370</sup> Ntshanga perhaps also cultivates this tone in order to reflect the character's background in HIV research. When he is leaving his job after becoming infected, his French boss tells him "[he] could sit on [his] arse at home if [he] wanted to [...] I understood his method. It was important for people in our profession to maintain a casualness around the virus. Even back then, we had to apply reins on how we expressed ourselves on the issue. There was the stigma to bargain with. Even in the most controlled cases, when mishandled, empathy could register as a cause for despair in a patient" (Masande Ntshanga, *The Reactive* (2017), p. 133) Arthur Frank similarly notes that "one of the most important aspects of the physician's performance is refusing to 'collude' with the patient" (Arthur Frank, *The Wounded Storyteller* (2013), p. 82) by offering too much sympathy.



relative cultural hegemony the ANC exercised on black South African imagination ... is waning”.<sup>371</sup> In particular, antiretroviral treatment is invoked by Coovadia and Ntshanga to reflect the unequal ways in which the ‘new South Africa’ has been experienced by different social groups. I discuss the portrayal of HIV/AIDS in each individual novel in turn below, considering how the treatment debate in South Africa, including its affordability and the ways in which it reveals ongoing systematic inequalities and oppressions, intersects with the novelists’ perception of the economic and psychic contradictions of the new nation.

### **Personal to political denial: Imraan Coovadia’s *Tales of the Metric System***<sup>372</sup>

Two of the ten stories in *Tales of the Metric System* (2014), Coovadia’s fictionalised sweep through recent South African history, depict the social effects of HIV/AIDS in ways designed to allow the novel to comment on the psychology of the post-Apartheid nation. The disjoint between the needs of his characters living with HIV/AIDS, and their treatment by those close to or responsible for them, renders how unhealed social harm and unresolved issues between groups subsist, despite the equalising language of the new Constitution. The epidemic largely manifests through dialogues; a technique that allows Coovadia to tell the story through a range of characters with diverging personal and professional motivations and access to knowledge, and any limitations in the exposition is equally attributable to what the characters wish to share or conceal. (He writes in his essay collection *Transformations* that “writing privileges individual judgement, and resists collective understandings”).<sup>373</sup> My examination

<sup>371</sup> Achille Mbembe, ‘Achille Mbembe on The State of South African Political Life’ (2015), <<https://africasacountry.com/2015/09/achille-mbembe-on-the-state-of-south-african-politics/>> [Accessed 28th August 2018]

<sup>372</sup> As the novel is not currently published in the UK, I quote from the text at some length for clarity.

<sup>373</sup> Imraan Coovadia, *Transformations: Essays* (Cape Town: Umuzi, 2012), p. 80.

of key interactions in the novel reveals how Coovadia imagines the epidemic to have been constructed at this discursive level within his rendering of the nation's journey from 1970s Apartheid to the modern day. Through these dialogic exchanges, the reader witnesses the confrontation of different epistemic perspectives and the turn-by-turn exercising of power in producing specific HIV/AIDS narratives.

The story 'Sparks (2003)' – briefly discussed above in relation to its characterisation of Thabo Mbeki - has what may seem to be a companion or precursor story in the '1995' story 'King Midas'. Linked by certain shared characters and themes, the chronologically later story is foreshadowed by the gnomic exchange that closes the story 'King Midas', between two characters, Sanjay and Victor, who meet at a Rugby World Cup after-party at the house of the 'Deputy President' Thabo Mbeki:

- I told you my life is over from today.
- You must be sure to choose the right woman. I happened to be lucky. But like tonight, she works very late in the hospital. They're seeing a lot of unusual cases in the wards.<sup>374</sup>

'Sparks' takes place in its entirety within these same wards. Having been glimpsed briefly at the party, the character Sparks takes centre stage amid a new orbit of cast members which includes the now President ('the Chief') and Victor's wife Ingrid Ndlovu. An exchange staged between "Dr Ndlovu and Dr Gerhard, the specialists in charge of [Sparks's] treatment" presents the reader with an example of official HIV/AIDS knowledge being produced in action:<sup>375</sup>

<sup>374</sup> Imraan Coovadia, *Tales of the Metric System* (2014), p. 241. Sanjay's self-proclaimed death sentence is his hyperbolic response to the news that his girlfriend is pregnant, following what we can assume to have been unprotected intercourse. As a narrative counterpart to the HIV-positive Vish, the fate of the cousins ingrains a thematic/discursive relationship between sex and risk that the AIDS epidemic would make increasingly unavoidable.

<sup>375</sup> Ibid, p. 218

Dr Gerhard held up the scans to the light, one after the other, and looked satisfied. He held them out to his companion.

- I believe we are making progress.
- I don't know what you mean by that, Dr Gerhard. I can also read a chart and to me this doesn't tell the same story.
- I am stating that we are making progress. You can see for yourself, Ingrid [...]
- So you think this man is on the road to recovery?
- Listen to my assessment, Ingrid. He is coming back from severe malnutrition. I am not saying our friend will celebrate his hundredth birthday. [...]
- I am looking at the same charts and, in my opinion, he will be lucky to be alive tomorrow unless something drastic changes.
- Ingrid, I am not interested in politicising the science this early in the morning. We have our instructions to avoid poisoning him with anti-retrovirals. Within those parameters, within those conditions that have been set by the patient, let us try to be responsible physicians.

Ingrid wanted to laugh out loud. They were letting a man die in a room two floors above their heads because the politicians didn't believe in the existence of his disease.<sup>376</sup>

In this conversation, the 'story' over which the two doctors wrestle is both the fate of Sparks (which readers familiar with the connection to Parks Mankahlana will already know), and the story of ART in South Africa. Whether or not Sparks survives without the antiretrovirals would provide strategic ammunition for each side of the AIDS debate: "His health, after all, was a matter of state interest [...] Cabinet secretaries and panels of scientists followed his case histories. Diplomats stood ready at the United Nations in New York to announce his

<sup>376</sup> Imraan Coovadia, *Tales of the Metric System* (2014), pp. 316-317.

return from the boundaries of the dead”.<sup>377</sup> Therefore, the foreign doctor’s insistence that he is not “politicising the science” is belied by his arbitrary misreading of the evidence, and moreover his attempt to invalidate Ingrid’s epistemic independence: “You can see for yourself, Ingrid” (p. 316). During the exchange, he becomes progressively more imperious in response to Dr Ndlovu’s objections, from asserting his position as a hypothetical (“I believe we are making progress”) to a command (“Listen to my assessment, Ingrid” (p. 306)). As we are given access to her unspoken thoughts, our readers’ sympathy is aligned with Ingrid, whose interpretation of the chart we know to be more trustworthy than Dr Gerhardt’s, and whom presumably conveys the author’s perspective.

Sparks, in this snapshot of history, is presented as a victim of political players and their hubris. Nevertheless, Coovadia also complicates the easily drawn comparison of the HIV/AIDS crisis to a second Apartheid, showing how his character’s freedom was ironically circumscribed not by the political events or tyrannical systems of human sorting that he lived through, but by a microscopic virus insensible to the social identity of the body that it occupies. In fact, a poignant juxtaposition shows how the dramatic events of history had blown wide Sparks’ horizons, and it is only after the struggle for freedom had been won, giving him the time to consult a clinic about “the cough that went on for two years” (p. 305), that his autonomy is taken away from him.

During the illness he had lost the freedom of the second and third dimension. The space in which he once lived had been as extensive as the continent across which their politico-military network extended [...] During his illness the space of his existence contracted to the halls of the hospital and cafeteria, from the whole of the hospital to this particular wing on the

<sup>377</sup> Ibid, p. 300.

top floor, then to his room, then the bed, the length of his body, and now to the centimetre behind his forehead.<sup>378</sup>

In ‘King Midas’, meanwhile, Coovadia depicts how even at the moment of celebration (South Africa’s hosting of and triumph against the All Blacks at the 1995 Rugby World Cup, just one year into the new democracy, was felt to define the nation’s new era of reconciliation and invulnerability), HIV/AIDS was already making its mark within South African society. Ashok, unlike Sparks, has been able to take advantage of the new opportunities for non-Europeans and has become a wealthy businessman. As the title of the story suggests, he flaunts his new riches, flying his family to watch the Rugby World Cup final at Ellis Park in Johannesburg. While in town, he arranges to meet his estranged son Vish, whom the family knows - although does not openly acknowledge – to be homosexual. From a shared origin point, the lives of the two cousins have drastically diverged, and the characters are purposely set up as foils: on meeting, Sanjay takes in “his cousin, who was almost exactly the same age as [him], almost the same height, but who now, judging by the looks of him, weighed exactly half as much”.<sup>379</sup>

While Ashok, the character to whom the title refers, is away from the table making a phone call, the following exchange between the cousins makes evident that Vish’s emaciation signifies he is living with HIV/AIDS:

<sup>378</sup> Imraan Coovadia, *Tales of the Metric System* (2014), pp. 298-299. Yet in another sense, Coovadia’s dramatization of the epidemic through a man so close to power does emphasise a parallel between the political and viral persecution forms of destruction. Sparks’ description of how his world slowly shrank mimics the National Party’s gradual removal of freedoms from indigenous and non-European South Africans, using the racial ideology of white supremacy to prevent people from occupying certain spaces, moving freely through other spaces and essentially to confine people within the limits of their own bodies. As a patient wholly in the power of others, the chart has become his story.

<sup>379</sup> Imraan Coovadia, *Tales of the Metric System* (2014), p. 225.

You must get the proper attention, man, Vish. Your father knows every Indian doctor in Natal because, at some point, he has sold a Mercedes to each and every one of them. And who can you trust if not an Indian doctor?

- The minute I go into the clinic it is as good as a death sentence. I am not stupid, Sanjay. There is no treatment for whatever is wrong with me. You know I worked in a hair salon on Berea Road for two years after school? You won't believe, not one of the men I worked with is still alive. White men, black men, Indians, coloured, the same. All gone.

- I am going to talk to uncle. This is something he can fix immediately.

- My father can't fix this. But I will give him a chance to help if he wants. There is a private clinic in Bryanston which is looking for patients for a new treatment. I don't know if he wants to help. You can convince him there. I thought it's worth a shot to ask him. I don't know what I have left to lose.

- I don't know what Uncle Ashok has done that you can doubt his willingness to help. He and your mother are the pillars of the family.

- I can't talk about that here. One day, when you are ready to accept the truth about my father, you will see for yourself. You will see that my father killed your father.

- Don't be melodramatic. He simply drew the line at some point and then refused to lend any more money. I don't blame him for that.

- One day you will find out the real story.<sup>380</sup>

Having rejected the materialistic and conservative (likely homophobic) values of his family, Vish had found a community where the ironic colour-blindness of HIV/AIDS was cruelly made obvious: "White men, black men, Indians, coloured, the same. All gone" (p. 226). As in

<sup>380</sup> Ibid, pp. 226-227.

‘Sparks’, the existence of the virus makes a mockery of attempts to separate humans into impermeable racial categories.<sup>381</sup> (The line also echoes an earlier story, in which Durban beach-goers found jellyfish stings to provide another faintly absurd leveller: “In seaside suffering, for once, there was no preference paid to colour. Black, white and brown stood in the same line for treatment”).<sup>382</sup> Although leaning perhaps slightly on an image of PLWHA being those who live (either by choice or not) on the margins of society, Coovadia’s technique of connecting his characters throughout *Tales of the Metric System* disallows the imaginative social separation of PLWHA. In his novel, the characters living with HIV/AIDS are the son of a prosperous, well-connected businessman and the right-hand man to the President, not stereotypes confined to their fate by poverty and lack of agency.

At the same time, the readers are brought to view how imaginative separation from PLWHA takes place within the other characters. It is unclear whether Sanjay understands what Vish refers to by the euphemistic phrase “whatever is wrong with me” (p. 226), but he does not enquire further or offer sympathy for Vish’s losses, instead repeating his faith in the ability of his uncle - and therefore, money - to “fix immediately” (p. 226) his cousin’s problems. Ashok, on his return, also fails to admit to himself the blatant fact that Vish is seriously ill, dismissively asking “Who has an appointment at the same time as the Rugby World Cup?” (p. 227). The self-serving neglect of those with HIV/AIDS in the novel – portrayed by Coovadia both in how the outright denial of Mbeki and the ANC government acts upon the

<sup>381</sup> Giuliana Lund points out that in Apartheid ideology, literal contagion in the form of disease fuelled paranoia about intercourse between persons, which “haunt[ed] the dream of pure difference” (Giuliana Lund, ‘Healing the Nation’ (2003), p. 95). She cites Rene Girard’s identification of how in literature and myth, “plague is universally presented as a process of undifferentiation, a destruction of specificities ... Social hierarchies are first transgressed, then abolished. Political and religious authorities collapse...” (cited in Lund 2003, p. 96). In this context, where the collapse of authority and false hierarchies was a desired event, HIV takes on an uneasy, ambivalent meaning. The inequitable state of healthcare however ensured that undifferentiating outcomes were short-lived.

<sup>382</sup> Imraan Coovadia, *Tales of the Metric System* (2014), p. 112.

body of Sparks (and by extension, those of South African PLWHA in general), and the wilful blindness of Ashok to his son's 'thinness' – undermines the idealistic picture of a clean break from the endemic oppressions of the old regime.<sup>383</sup> Equally, in both 'Sparks' and in 'King Midas', characters' investment in that idealistic picture is shown negatively to affect their ability to empathise with PLWHA. The 'Chief' invokes his own reputation ("Jimmy Carter will be on my head", the 'Chief' tells Sparks as he lies in his hospital bed)<sup>384</sup> while Vish's disease is seen by both Sanjay and Ashok to be in some sense disloyal to his parents ("the pillars of the family" (p. 227)) and to the nation, embodied on this day by the fate of the rugby team:

- Today this country has the opportunity to put the bad history behind it. Vish, when is the last time your mother saw your face? [...] Come tonight and you can also put her mind at rest.
- We used to boycott rugby. We used to pray for the teams from other countries to win over the Springboks. In one year they have turned to gold in your eyes?<sup>385</sup>

The story's title 'King Midas' is ultimately revealed to refer not only to Ashok's business acumen (and, it is implied, light chicanery), but also the doomed desire to gild over any and all cracks in South African society. Vish reminds his father how under Apartheid, the rugby team was a powerful symbol of racial division, as the sport prohibited players of colour from

<sup>383</sup> Didier Fassin writes of Puleng, a woman whose story he recounts in *Bodies That Remember*, "With AIDS in the new democracy, she discovers *new forms of violence*: neighbours shun her when they learn what ails her; the government refuses to make effective therapeutic drugs available; she is to die in near-total destitution because the disability grant she applied for has not come; there is no hope of palliative care to soothe her last days" (Didier Fassin, *When Bodies Remember* (2007), p. 24, my emphasis).

<sup>384</sup> Imraan Coovadia, *Tales of the Metric System* (2014), p. 304.

<sup>385</sup> Ibid, p. 227.



representing the country.<sup>386</sup> Nelson Mandela stepping into Ellis Park stadium wearing a green Springboks jersey would prove to be an extraordinary nation-unifying moment, that had the temporary effect of neutralising the symbol's original connotations; nevertheless, it of course did not completely "put the bad history behind" (p. 227). Vish's fleeting and frail presence in the novel – and his father's access to good doctors and private clinics that he seeks - evokes how economic inequality in the country continues to determine life outcomes, in ways that align with interconnected systems of domination.

### **Treatment vs commodity: ART as sign of late capitalism**

On the occasion of *The Reactive*'s publication in the United States, the American magazine *Vice* published an excerpt from the novel under the leader 'Read this Story about an HIV-Positive Drug Dealer in South Africa'.<sup>387</sup> This title could be seen as somewhat sensationalist, even considering the magazine's modus operandi, given that Nathi's 'product' is life-saving anti-retroviral medication rather than illegal narcotics. At the same time, it brings out a leitmotif within the HIV/AIDS treatment story - not only in South Africa but globally – namely, how treatment exists at the borderline between humanitarian efforts and a profit-making enterprise. In a global society where, as the anthropologist Jean Comaroff writes, "healing is increasingly vested not merely in corporate bioscience but in the drug as ur-commodity",<sup>388</sup> it is not entirely incongruous to see that both of the novels examined in this

<sup>386</sup> The racial transformation of the South African team has been slow, and the issue continues to be politically charged. By 2019, the Springboks' coach Rassie Erasmus is required to select a team with at least 50% black representation.

<sup>387</sup> Masande Ntshanga, 'Read This Story About an HIV-Positive Drug Dealer in South Africa' (2016), <[https://www.vice.com/en\\_us/article/4wbpzq/read-this-story-about-an-hiv-positive-drug-dealer-in-south-africa](https://www.vice.com/en_us/article/4wbpzq/read-this-story-about-an-hiv-positive-drug-dealer-in-south-africa)>, [Accessed 29<sup>th</sup> August 2018].

<sup>388</sup> Jean Comaroff and John Comaroff, *Theory from the South* (2012), p. 188.

chapter dedicate more imaginative space to the practicalities relating to the consumption of ART than to direct representations of the experience of living with HIV/AIDS. As ARVs emerged as the only proven tool in the fight against deaths from AIDS, these drugs came to “embody ever more succinctly the means of life itself”.<sup>389</sup>

As discussed previously in this thesis, the Big Pharma corporation’s desire to control the means of production had provoked the ANC to challenge the industry, with some success. Even in the wake of the South African government’s reforms within importing and production law, less than 2% of drugs consumed in Africa are currently produced on the continent, with serious ongoing consequences for affordability and access.<sup>390</sup> However, the collapsed distinction between society and the market brought about by neoliberalism makes persuasive an over-simplistic conflation of drug access with health and patient empowerment . It is notable that despite the unavailability of ARVs looming so large in this period of South African history, both of the novels discussed in this chapter portray characters who are able to access treatment, yet choose not to (even though Sparks’ choice is not exactly within his own hands). By centring characters who renounce the life-saving technology of ARVs, the novels upend the affirming and cathartic narrative arc of the restitution narrative that Arthur Frank links closely with the marvels of modern medicine. As such, they go beyond depicting AIDS as a straightforwardly biological life-or-death situation to examining the kind of opposition that Comaroff identifies between ‘bare life’ and “a socially meaningful existence”.<sup>391</sup>

<sup>389</sup> Jean Comaroff and John Comaroff, *Theory from the South* (2012), p. 188.

<sup>390</sup> Tefo Pheage, ‘Dying from lack of medicines’, <https://www.un.org/africarenewal/magazine/december-2016-march-2017/dying-lack-medicines>, [Accessed 28<sup>th</sup> August 2018].

<sup>391</sup> Ibid, p. 182.

In *The Reactive*, the uneven and unfinished transformation of South African society is dramatised through the fates of its core characters, Ruan Russell, Cecilia (Cissie) Evans and Lindanathi Mda. Although the three friends are intellectual, imaginative, and have benefitted from middle-income upbringings and the opportunities of higher education which implicitly promise an upwardly mobile trajectory, they inhabit a drifter-like existence that reflects both their disillusionment with such ambitions and the failure of the economy and institutions to provide meaningful prospects in the first place. After dropping out of the journalism degree on which he was originally enrolled, Nathi retrained in the sciences and gained work at the HIV research clinic where he would later become infected with the virus. His subsequent writing job having been made “obsolete” (p. 139) by the disruptions of the digital content economy, he now works part-time in a video rental store (another imminently obsolescent technology). Ruan meanwhile has “ruined his CV” after losing a series of jobs due to “a slew of unforeseen panic attacks” (p. 68), and found himself stuck working for a family member, for which he receives just enough reimbursement to subsist in Cape Town. Cissie, the only character whose job as a teacher seems to bring her fulfilment, receives the material rewards of an uninspiring flat in which “most of the walls are stained [...] and the floors are cracked, too. [...] It’s what makes it affordable for her to rent a flat in this area” (p. 10).

These biographical snippets are revealed to us slowly, often less apparently as character exposition than as after-thoughts (“I have this job I guess I should have mentioned” (p. 59)). When we are first introduced to the three friends they appear to be wholly occupied by getting high and the rather labour-intensive work of selling Nathi’s ARVs: cooking the glue for the advertisement posters, defrauding the printer companies of the ink to print them, and scouring support groups all over Cape Town’s suburbs for buyers. The nature of ARV drug as commodity is thus quickly established from the start, and Ntshanga accentuates this by

situating their hustle among a flurry of other exchanges and transaction metaphors.<sup>392</sup> For the post-Apartheid generation, it is understood that even the marker of race has a calculable value: “It didn’t take much to go to school for free, in those days, or rather to trade on the pigment we were given to carry” (p. 3). The narrator’s offhand alertness to how this socially constructed feature outside of his control - this ‘pigment we were given to carry’ - could so drastically and arbitrarily affect his fate in South Africa provides a further insight into understanding the apparent nihilism and opportunism of the characters.

In addition, the cynicism that came to taint Western AIDS drugs after the South African government’s struggle to obtain affordable or generic pharmaceuticals could be seen to seep into the ways that the character navigates his diagnosis. For Ntshanga, the apathy that his protagonist presents towards ARVs is related to wider contradictions between the maintenance of one’s (quality of) life and the inaccessibility of such options to large swathes of the population. As such, *The Reactive* can be seen to encompass a paralysing cultural anxiety, as explained by the author in an interview:

To me, a lack of motivation has always felt like a legitimate response to capitalism, especially in societies where the consumption is exacerbated by keeping the culture as ahistorical as possible. In cases like those, it can even seem humane to me, to hinder your own participation, almost in the Buddhist sense, where allowing a strong desire to manifest at all costs leads to conflict; to the harm of someone else. For my characters, I guess nothing in

<sup>392</sup> Nathi, Cissie and Ruan trade the profits they make from selling ARV drugs for recreational drugs (those mentioned in the novel are marijuana, industrial-strength glue, paint thinner, cigarettes, alcohol, methamphetamine) which are in some cases illegal. More pertinently, they are products which are – in opposition to ARVs - positioned against life, although the three friends do not entirely accept that definition. The support group they first meet at is designed for PLWHA and drug misuse; when the topic of drugs arises, Nathi notices Ruan’s smirk and Cecilia’s eye-roll, and “didn’t need any more evidence for our kinship” (p. 28). Nathi’s narration evidences his awareness of the toxicity of some of their behaviour: “Ruan’s cheeks pull inward as he drags on his cigarette [...] I watch the carcinogens leaking out of his body” (p. 65)), but the author insists that the novel “is not a cautionary tale on drug abuse [...] and in fact makes no comment at all about drugs” (Masande Ntshanga (2015), no pagination).

their immediate vicinity warrants that kind of desire, and because of their removal from history, and from history's significant moments, they can't channel this feeling into creating a counter-narrative — a proposition for a different society — because they don't have the vocabulary for it.<sup>393</sup>

In *The Reactive*, the deliberate refusal of ART therefore signals a radical position, beyond the schema of HIV/AIDS beliefs, denial or stigma. Nathi is seen to voluntarily withdraw from the privileges offered by his life, most overtly through infecting himself with HIV. Although Cissie and Ruan are not living with the disease, their stories and coping mechanisms also betray hints of trauma in their past that have bred a nonchalance towards their wellbeing ("This was the same Ruan who, with two cigarettes in his mouth, would tell you that every day the tobacco industry recruits three thousand new smokers to compensate for the ones it kills" (p. 109)). The theme of withdrawal presents both a philosophical and ethical statement, which is reinforced by the opting-out of privilege by a minor character Thobile, about whom Cissie is making an audio-documentary:

Last year, Thobile quit his job to live on eight rand a day. It was in solidarity with his community, he said, and in the clips Cissie played back for us at West Ridge, we could hear the difference in his tone at the beginning of the experiment, and then a month later. Cissie, who planned to paint a portrait of him [...] said he lost eight kilograms in three weeks (pp. 78-79).

The rejections can be interpreted as standing in for a larger distaste for the vast inequality in South Africa that undermines the promise of the Constitution of equal opportunity and

<sup>393</sup> Masande Ntshanga, 'Writers Can't Control Everything Related to Their Work' (2015), <<http://bookslive.co.za/blog/2015/02/03/writers-cant-control-everything-related-to-their-work-interview-with-masande-ntshanga-author-of-the-reactive/>>, [Accessed 29<sup>th</sup> August 2018].

freedoms for all.<sup>394</sup> Ntshanga identifies the dilemma for his characters as an inability to partake in the pretence of freedom, at the expense of others, while at the same time lacking a liveable alternative to that enshrined in idealistic rhetoric of the Rainbow Nation. (This new counter-narrative has arguably manifested through the Rhodes/Fees Must Fall student protest movements and the rise in popularity of the more radical Economic Freedom Fighters (EFF) party). After giving up his employment, the twenty-eight-year-old Thobile discovers just how little opportunity there is for him to productively use his graduate skills in the township of Langa, just outside Cape Town: Nathi recalls that in one of Cissie's tapes, Thobile "described how he hadn't robbed anyone, yet" (p. 79).

The literary critic Alla Ivanchikova has drawn comparisons between post-Soviet Union Russia and post-Apartheid South Africa, as two societies whose massive social transitions were greeted with great excitement that changed to disillusionment. In both new nations, she perceives, the hoped-for end to poverty and oppression was hindered by "the rapid integration of marginalized and isolated economies into transnational market economy, which was experienced as a new form of colonialism".<sup>395</sup> The disintegration of Apartheid and communism were furthermore connected in that the collapse of the Soviet Union had played a significant part in the outcome of the anti-Apartheid struggle: South Africa was one of many proxy locations in which the Cold War played out, as in exile the ANC party had drawn on both the tenets and the economic and military strength of the Soviet Union, and the

<sup>394</sup> In 2018, the World Bank estimated that South Africa was the most unequal country in the world, with a Gini co-efficient based on income data of 0.62. Almost two and a half decades after the end of Apartheid, more than half the country still lives below the national poverty line, and 70.9% of the nation's wealth is owned by just 1% of the population. (Victor Sulla and Precious Zikhali, 'Overcoming Poverty and Inequality in South Africa: An Assessment of Drivers, Constraints and Opportunities' (Washington, D.C.: World Bank Group, 2018).

<sup>395</sup> Alla Ivanchikova, 'Commodity and Waste as National Allegory in Recent South African and Post-Soviet Fiction', *CLCWeb: Comparative Literature and Culture* 13(4), (2011), p. 2.

National Party similarly had accrued the support of Western states which wished to prevent communism's spread. As South Africa entered into democracy, therefore, the ANC was also forced to find alternatives to its founding socialist principles. Ivanchikova argues that "the ideological vacuum and uncertainty that defines the post-socialist or post-Apartheid condition [is] a situation that consumerist ideology promises to resolve, but fails".<sup>396</sup>

The city of Cape Town, where *The Reactive* is set, reveals the failures of that ideology particularly starkly, for those who care to see the "enclaves of the third and fourth worlds" situated just beyond the luxury and affluence of the city centre.<sup>397</sup> Indeed, Nathi shows us, the capitalistic space of the city contains and conceals the violence of colonialism in ways which the new longed-for present cannot fully abolish:

I lean against the lift wall and think of Greenmarket Square again, and how, not too far from here, and less than two hundred years ago, beneath the wide shadow of the muted Groote Klerk, slaves were bought and sold on what became a wide slab of asphalt, a strip divided by red-brick islands and flanked by parking bays where drivers are charged by the hour; behind them, yesteryear's slave cells, which are now Art Deco hotels and fast-food outlets (p. 73).

In admitting the reader into Nathi's stream-of-consciousness narration, Ntshanga creates not only a sense of intimacy but also a subtle expansion of their historical awareness. The injustice that is literally built into the environment – and the need to resist the easier option of historical amnesia - presents itself as a mental burden carried by the descendants of the

<sup>396</sup> Ibid, p. 3. In one story-chapter of *Tales of the Metric System*, 'The Soviet Embassy (1985)', one character tells Ann, a South African exiled in London: "In your country, from what I do know, money is the great equaliser [...] Despite all this talk of socialism and communism, you might end up as the most capitalistic country in the world" (2014, p. 146).

<sup>397</sup> 'Alla Ivanchikova, 'Commodity and Waste as National Allegory' (2011), p. 3. (Ivanchikova is here writing about Cape Town in the context of K. Sello Duiker's *The Quiet Violence of Dreams* (2001)).

formerly disadvantaged. By inserting these ideas into Nathi's internal monologue, as the three travel together to a mutual friend's party, the reader is also deftly enabled to witness a level of the epistemic disconnect that exists between groups in South Africa. It is perhaps this imbalanced sensitivity towards the country's history that causes Nathi to think to himself, when Cissie proclaims at the beginning of the novel that the three of them are "basically slaves" (p. 19), that:

The three of us aren't slaves. Ruan, Cissie and I each wrote matric in the country's first batch of Model Cs.<sup>398</sup> In common, our childhoods had the boomerangs we used to throw with the neighbourhood kids, the rollerblades and the buckets of space goo. The Sticky Hands with their luminous jelly fingers, each digit rumoured to be toxic, which we clotted with wet earth and on the first day back from the store and threw into our green pools for cleansing. The Grow Monsters which we watched expanding inside our toilet bowls with awe, and the tracks we dug for our Micro Machines... (p. 20).

The lifting of anti-Apartheid trade sanctions brought a flood of international goods and cultural products into the country for the first time, and such new consumer items themselves came to symbolise change through "the disappearance of individual identities in the universal commodity status", blurring the distinction between novelty and progress.<sup>399</sup> Through this litany of trade-marked brand-name toys, we view how the democratisation of South Africa coincided with its increased commercialisation. The levelling childhood experience of the three friends not only erases racial divides but national ones, as the brand names we read could invoke suburban upbringings in a multitude of settings: in Ntshanga's words "keeping the culture as ahistorical as possible".<sup>400</sup> Yet the globalising facility of pop cultural cachet is

<sup>398</sup> Previously white-only government schools.

<sup>399</sup> Alla Ivanchikova, 'Commodity and Waste as National Allegory' (2011), p. 5.

<sup>400</sup> Masande Ntshanga, 'Writers Can't Control Everything Related to Their Work' (2015), no pagination.



simultaneously exclusionary, as Nathi recalls the comparative deprivation of his younger half-brother Luthando, who never possessed those common objects, and “didn’t know what a spinning top was before I gave him mine” (p. 20).

Ntshanga thus uses Nathi’s proximity to the continuing dispossession of many – particularly black - South Africans to intuitively keep these contradictions in South African society at the forefront of the narrative. Although Ruan and Cissie feature most within the novel, others continue to exercise claim over Nathi’s consciousness from ‘off-stage’: his uncle Bhut’ Vuyo interpolates himself into Nathi’s life through text messages, and Luthando’s presence is frequently triggered through memory, calling him - like Thobile - to bear witness to the community he has left behind.<sup>401</sup> The cognitive dissonance produced by the two spheres’ coexistence is powerfully encapsulated in a reflection that Nathi has towards the end of the novel, after his return to Du Noon. While Ntshanga emphasises the real-world proximity of the township to the privileged urban centre of Cape Town (“It takes the taxi less than an hour to reach Du Noon” (p. 165)), he also depicts the extent to which the places seem socially, even notionally, sealed from one another. After a few days, “[t]he rest of Cape Town starts to feel distant [...] surrounded by uncertainty and receding into memory” (p. 168) and even Cissie and Ruan – the three of whom had until this point been depicted to us as an inseparable unit, whose boundaries are almost indeterminate – fade from his consciousness, as though irretrievably lost, instead of just a short journey or a phone call away: “I think about where Cissie and Ruan could be on a day like today [...] Then I shrug and wish the two of them the best” (p. 173).

<sup>401</sup> Andrew van der Vlies describes Bhut’ Vuyo as “a voice of moral authority and mediated tradition in the text” (Andrew van der Vlies, *Present Imperfect: Contemporary South African Writing* (Oxford: Oxford University Press, 2017), p. 161).

In contrast to Thobile, however, Nathi's homecoming to Du Noon is presented not as an act of downward assimilation but as an act of renewal and recovery. By the close of the novel, Nathi has redeemed himself in the eyes of his family by taking part in the traditional initiation (*ulwaluko*) that he had promised to accompany Luthando to a decade earlier. He has also found love with a girlfriend, Esona; together they worship "at the altar of her caution" (p. 183) with condoms brought back from the local store where he has found employment. If, as Nancy Armstrong suggests, the British novel promoted a mode of subjecthood achievable through the trope of upward social mobility, *The Reactive* rejects the desirability of an individualistic journey that necessarily leaves behind a majority.<sup>402</sup> It is a narrative of selfhood founded on recognition by one's community, rather than by distinguishing oneself from "strangers in the metropolis" (p. 139). In its inverted direction of movement, Ntshanga's novel also upturns the assumptions of "European historicism [which] allows only one trajectory to non-Western societies if they are to be recognized as part of the grand human story: they must undergo a visible metamorphosis – fast or slow, effective or otherwise – to Western capitalist modernity".<sup>403</sup> Nathi's view of the society which he navigates and the HIV/AIDS epidemic finds plenty to criticise, but the frames through which he apprehends them are not imported. After all, the ARV plotline indicts not only the South African government's policies but the operations of the global market and capital, whereby the medication easily penetrates South African borders to reach those with means to procure it.<sup>404</sup>

<sup>402</sup> Armstrong, Nancy. *How Novels Think: the limits of British individualism from 1719-1900* (New York, Chichester: Columbia University Press, 2006).

<sup>403</sup> Dipesh Chakrabarty (2000) glossed in Jean and John Comaroff, *Theory from the South* (2012), p. 3.

<sup>404</sup> The amoral, impervious workings of the market are shown not only through Nathi, Ruan and Cissie's dealing in pharmaceuticals, but are also portrayed through the mysterious masked man who purchases the friends' entire stock in order to launder his money, and who finally uses them to convey cash and a forged passport to his school-aged daughter so that she can leave South Africa behind for the Global North. ("So who knew? Cissie says. You're a Canadian" (p. 147)).

In both form and content, *The Reactive* presents a “reflection on the contemporary order of things approached from a primarily African vantage”.<sup>405</sup> Seemingly (and no doubt, studiedly) unconcerned with the “prior discourse” that Achille Mbembe found other African writers to need endlessly to negate, Ntshanga’s novel can be seen in many subtle but powerful ways as a ‘narrative from the South’.

### **‘Last Life’: Phenomenology as style in Masande Ntshanga’s *The Reactive***

As readers, we are first made aware of Nathi’s positive diagnosis when he relates dispassionately, with a dose of wry anti-climax, how “I enrolled at the Technikon<sup>406</sup> in town, where I got my science diploma and my sickness” (p. 3). The apathetic attitude of *The Reactive*’s characters towards the ideals of the new nation is mirrored in the novel’s narrative style. Throughout, Ntshanga’s descriptions of the sensations created by both natural and manmade phenomena, and by the drugs which mediate his friends’ lived experiences and consciousness, are rendered with artistic sensitivity to detail and an occasionally jarring emotionlessness. This strategic employment of affect is a key element in the stylistic success of the novel, and its implicit challenge to the metanarrative that there is a prescribed way in which literature should deal with illness and with social crises such as the AIDS epidemic. Although Nathi, like Vish, is euphemistically described as “bone-thin” (p. 11), physical symptoms and experiences of living with HIV are largely glossed over or deliberately left indistinguishable from those produced by the narcotic highs and comedowns that he and his friends “don’t manage to stay in between for long” (p. 16).

<sup>405</sup> Jean and John Comaroff, *Theory from the South* (2012), p. 2.

<sup>406</sup> A technical college established as a ‘technikon’ following the Technikons Act of 1976. The university now known as the Cape Peninsula University of Technology (CPUT) was created in 2005 (two years after the events of *The Reactive*) from the merger of the Cape Technikon and Peninsula Technikon.

It is not insignificant that the over-determined three-letter abbreviations ‘HIV’ or ‘AIDS’ are barely voiced in the novel – Nathi prefers to eschew the medically authorised terminology for vaguer (and more personal) references like “my sickness” (p. 3) or non-conventional variants like “HI Virus” (2014, p. 34) or “the immunodeficiency virus” (p. 17). On the sparing occasions the term HIV is articulated,<sup>407</sup> it feels purposefully - almost impertinently - meted out to provoke an emotional reaction. The second time it occurs, Nathi is telling the readers about Cissie’s impatience with a fellow member of the support group: “I remember how she once asked us why he didn’t just get HIV already. Maybe it was an awful thing to say, but Ruan and I laughed because it was true [...] We could’ve pulled a lot of money out of him” (p. 37). Given the difficulties inherent in representing HIV, this irreverence towards the official jargon acts on a deeper level as a kind of resistance to the dominant episteme.

In this section, I read Ntshanga’s apparently deliberate abstraction of HIV/AIDS in *The Reactive* as a phenomenological portrayal of illness (or rather, a phenomenological portrayal of HIV/AIDS as one illness among many), challenging tendencies towards ‘AIDS exceptionalism’ - as well as resisting expectations that African novels are “suffused with descriptions of hurt” in ways that may encourage voyeurism and appropriation.<sup>408</sup> As a tradition within philosophy, phenomenology argues that an account of human understanding can only be based on our perceptions of *phenomena*, as opposed to *pragmata* (the social meanings of things, or our interpretations of things).<sup>409</sup> The tenet common to different

<sup>407</sup> The acronym is only used eleven times in the entire novel, most of which are spoken within the hyper-scientific space of the laboratory, as if to locate its resonance within this discursive environment.

<sup>408</sup> Zoe Norridge, *Perceiving Pain in African Literature* (Hampshire: Palgrave Macmillan, 2013), p. 3.

<sup>409</sup> The school was first established by the German philosopher Edmund Husserl at the start of the twentieth century as “a way of navigating between the radically subjectivist and objectivist epistemologies of

proponents of phenomenology – that it must aspire to begin its inquiry at a point before abstraction – therefore has clear appeal to researchers working to delink knowledge from or to dismantle macro-narratives such as those discussed at the beginning of this thesis.<sup>410</sup> The novel’s downplaying of pain has the effect, nevertheless, not of minimising empathy towards PLWHA but rather expanding its field. In a scene set in a support group, members relate stories produced by drug dependency and the degrading effects of lifelong poverty, and Nathi diverges from his scepticism (being only there to score customers for their ARV hustle) to reflect:

Like most places filled with the sick and the dying, there’s always an opportunity to learn something about being a person here. Our parking lot turns into an academy at times, and we get educated on the survival of people like Leonardo and people like Linette, on people like Neil and people like Olive. Maybe it’s best for me to forget my own troubles and grow a greater sympathy for others. Like Cecilia, this could be what Bhut’ Vuyo wants from me. (p. 38).

The friends’ conception of ‘Last Life’ as a space of existential self-determination, and Nathi’s musings about the humanistic education provided by the support group, call to mind the philosopher Havi Carel’s statement that illness often “constitutes a violent invitation [...] to philosophize”.<sup>411</sup> Carel began her own scholarly project to (re)conceptualise illness after she

psychologism and naturalism” (Lisa Guenther, ‘Epistemic Injustice and Phenomenology’ in *The Routledge Handbook of Epistemic Injustice*, ed. by Ian James Kidd, José Melina, Gaile Polhaus Jr (New York: Routledge, 2017), p. 195) and developed further by existentialist philosophers including Maurice Merleau-Ponty, Jean-Paul Sartre, Simone de Beauvoir, Frantz Fanon and Albert Camus. It departs from mainstream analytical philosophy in several important ways, one of which being that it does not posit data as empirical or absolute, but rather “constrained by the conditions of the possibility of consciousness” (Havi Carel, *Phenomenology of Illness* (2016), p. 21)

<sup>410</sup> According to Hermann Schmitz, “the task of the phenomenologist is to access phenomena in the richness of perspectives in which they are at any time embedded – a task that may include the critique of illegitimate, distorting representations, ideas, theories and concepts”. (Herman Schmitz et al, ‘Emotions outside the box – the new phenomenology of feeling and corporeality’, *Phenomenology and Cognitive Science* 10(2), (2011), p. 244)

<sup>411</sup> Havi Carel, *Illness: The Cry of the Flesh*, (London: Routledge. 2008), p. 4.

developed a rare and incurable lung condition, lymphangiomyomatosis (LAM).<sup>412</sup> Her experience of diagnosis and treatment taught her “about [her] embodied existence, about people’s illness and disability, about people’s attitudes towards illness and disability, about the inability to speak of important things”<sup>413</sup>: topics which she argues are epistemically muted in mainstream society, discourse and philosophy. Her ongoing endeavour to develop a reparative framework, first in *Illness: The Cry of the Flesh* (2008) and developed further in *Phenomenology of Illness* (2016), thus enlists illness as a rich and rewarding tool for thinking about the human experience. A phenomenology of illness aims to remind us that it is not a philosophical or stylistic choice as to which way of understanding illness is best, but that only an understanding that pays attention to the lived realities can capture its nature at all. It forces us to acknowledge the “body’s practical and theoretical significance: [that] the body is inseparable from, and the condition for, any experience whatsoever”.<sup>414</sup> Contrary to seeing language or narrative as a prerequisite for understanding illness, phenomenology understands the body itself to be the medium.

This idea is captured stylistically in the prose of *The Reactive*, which is loaded with imagery drawn from the body. Ntshanga accords inanimate and abstract aspects of the world anthropomorphic capabilities and motivations, while individual limbs or constituents of characters’ bodies themselves frequently seem to possess an uncanny agency and autonomy from the person they ‘belong’ to, for example:

<sup>412</sup> LAM affects around three to five in every million women, and usually presents at approximately 35 years of age (although the mean age range is relatively wide). The disease is characterised by breathlessness as a result of abnormal growth of smooth muscle cells leading to loss of lung function and compromised oxygen transfer to the blood.

<sup>413</sup> Havi Carel, *The Phenomenology of Illness* (Oxford: Oxford University Press, 2016), p.6

<sup>414</sup> Ibid, p. 31.

“It didn’t take much to go to school for free, in those days, or rather to trade on the pigment we were given to carry” (p. 3)

“I lie back and watch my blood turn orange behind my eyelids. The grass spikes me between my ears and neck” (p. 53)

“I feel my thoughts branch out and scatter [...] as if each thought were tied to every molecule that comprises me” (p. 72)

“Cissie has these bad rashes [...] When she lifted her bottle, one of these scars looked at me” (p. 110)

As this handful of examples suggests, in addition to troubling the boundaries between life and death, health and illness, the world as rendered through Nathi’s eyes reveals other aspects of his (and our) embodiment to have outlandish and remarkable dimensions. Ntshanga achieves this persistent de-familiarisation of our automatic, everyday actions through what I see as a phenomenological attentiveness to the sensations and emotions which they produce. It is by prioritising the phenomena over their social meanings that he is able to so viscerally remind the reader of the miraculous, unlikely vulnerability and resilience of the human body.

By situating his protagonist’s diagnosis of HIV/AIDS in this way at an unexpected angle to illness and mortality, Ntshanga opens a fictional space in which to narrate the presence of the epidemic in South African society without allowing it to dominate. HIV/AIDS does prompt Nathi to reconceive of his identity as either victim or public activist, a journey that would be “amenable to mainstream American sensibilities in its assumption that pain must be made to yield uplifting lessons”.<sup>415</sup> The disease is allowed to occupy Nathi’s consciousness in the narrative only when he is receiving phone calls from his case manager, when he is at support

<sup>415</sup> Rita Barnard, ‘Oprah’s Paton, or South Africa and the Globalization of Suffering’, *Safundi: The Journal of South African and American Comparative Studies*, 7(3), (2007), p. 10.

groups, and in occasional moments of vulnerability (“What helps, of course, is to try to forget about it as much as possible. Which is what I do.” (p. 17)). Ntshanga’s novel takes some of its power from a kind of denial: not that AIDS exists, but a denial of the pessimism that discursively confines Africa to issues. In one scene, Nathi recalls how:

in my fourth year of high school, my biology teacher took a flying class on the coast of Natal, and discovered a lesson for us in the air above Richards Bay. Her name was Mrs Mathers, and when she returned to class the following week, she told us how the Earth was gutted open with so many new graves for paupers that when the clouds parted, they revealed a view from the sky that looked like a giant honeycomb. Then she watched everyone’s expression [...]  
Our teacher told us each grave was meant to contain the bodies of twenty adults.  
She said to us, that is HIV. (pp. 148-49).

Although probably well-meaning, the teacher’s wish to provoke a reaction among her pupils appears slightly heartless, with its verging-on-exultant tone and the incongruous lyricism of the ‘giant honeycomb’. Through characters such as Mrs Mathers and Mary, the facilitator of the support group, Ntshanga establishes for the reader the ‘facts’ while at the same time enacting the novelist’s right to address social problems without falling in line with external assessments of those problems. In particular, he shows how the hectoring undertone of AIDS education can alienate and offend those ostensibly being engaged. In the support group, Mary shuts down one member with the ironic admonishment, “What we’re here for is to lighten each other’s burdens, not to spread lies from crackpots” (p. 44). Her follow-up with the platitude, “There’s no cure for HIV, but as you can see for yourself, it’s a condition anyone can live with” prompts the rest of the support group to “nod, doing our part like we’re meant to” (p. 45), in a way that is suggestive of the performativity and insincerity that can lie behind the preservation of the public transcript.



*The Reactive* represents Nathi's life with HIV/AIDS through an insistence on granular, tangible descriptions that trace the contours of sensations so closely as to detach them from an obvious cause. By doing so, it circumvents the conventional way of portraying illnesses that Carel identifies as the naturalist view, which sees illness as biological dysfunction, or a normativist view, which apprehends illness from the point of view of how society perceives the ill person.<sup>416</sup> Despite the differences between these two views, each has the effect of pathologising the ill person, reducing them into a category which obscures our ability to see the richness and diversity of experiences of illness. Equally, by virtue of the insider/outsider line they draw, they allow us to overlook the ordinariness and universality of illness. Close to the beginning of the novel, Nathi remarks, "of the three of us, I'm the one who's supposed to be dying" (p. 17). The overall effect is to whisk away the comforting cordon sanitaire between PLWHA and people not living with an HIV positive diagnosis; as if any of us can suppose we are not also dying. Nathi's dissociated, stoner-like acceptance towards the disparate events thus achieves something like what Susan Sontag hoped for in *Illness as Metaphor* (1989): "to calm the imagination, not to incite it. Not to confer meaning, which is the traditional purpose of literary endeavour, but to deprive something of meaning..."<sup>417</sup>

Within the field of literary criticism, the philosopher Maurice Natanson is perhaps the foremost scholar to employ phenomenology as an interpretive method. In *The Erotic Bird: Phenomenology in Literature* (1998), he discusses three twentieth-century European works of fiction: Franz Kafka's *The Metamorphosis* (1915); Thomas Mann's *The Magic Mountain* (1927); and Samuel Beckett's *Waiting for Godot* (1955), all of which he deems

<sup>416</sup> Havi Carel, *Illness: The Cry of the Flesh* (2008), pp. 11–12.<sup>416</sup>

<sup>417</sup> Susan Sontag, *Illness as Metaphor* (London: Allen Lane, 1979), p.101.

phenomenological because they suspend or disorient familiar aspects of lived experience. As he defines it, the phenomenological is “the notion of the ‘current’ of existence [...] that pulse of mundane, day-to-day life which throbs in the body of each human being but which is not noticed or remarked on until one’s ‘pulse’ is taken in an examination of some kind”.<sup>418</sup>

Equally important is the insight that these essential realities of our embodiment are almost always able to escape our attention until something is wrong: until some examination – which, in Foucauldian terms, would connect to some kind of bodily disciplining – is needed. Carel describes illness as bringing “normal processes and practices into sharp relief, juxtaposing them with cases of pathology and dysfunction”.<sup>419</sup>

It is perhaps unsurprising, therefore, that all three of the texts which he selects for exegesis in *The Erotic Bird* contain characters who are suffering from illness or some kind of otherwise disturbing bodily changes. In the tragicomedy *Waiting for Godot*, Estragon is eternally in agony due to his too-tight pair of boots, while Vladimir complains of prostate pain from an inability to pass urine (perhaps symbolising the current of existence literally diminishing to a stoppage). The other characters we encounter are also in some way afflicted: the slave Lucky speaks with an unidentified speech disorder, and his master Pozzo is mysteriously struck by blindness midway through the play.<sup>420</sup> Where the world of Beckett’s play is so bare as to be read as an unreal or allegorical space, *Metamorphosis* and *The Magic Mountain* throw into

<sup>418</sup> Maurice Natanson, *The Erotic Bird: Phenomenology in Literature*, (Princeton, New Jersey: Princeton University Press, 1998), p. 14. Already, the heft and resistance of embodied existence is compellingly present in Natanson’s language: the metaphor of the current, taken from Tolstoy’s short story, *The Death of Ivan Ilych*, melts into one of a specifically human pulse. (Schmitz’s preferred phrase is “the vital drive”) (2013).

<sup>419</sup> Havi Carel, *The Phenomenology of Illness* (2016), p. 2.

<sup>420</sup> It has been suggested that Lucky has a form of Parkinson’s disease: in Deirdre Bair’s biography of Samuel Beckett, the character’s original actor Jean Martin describes how a physician friend suggested the disease as a potential physiological explanation for the voice in the play-text. When Martin told Beckett that he was playing Lucky as if he were suffering from Parkinson’s, Beckett reportedly replied “Yes, of course”, and mentioned briefly that his mother had had the condition (Deirdre Bair, *Samuel Beckett: A Biography* (London: Simon & Schuster, 1990), pp. 448-449).

stark relief the taken-for-granted concerns of the worlds inhabited by the characters. Drawing connections between the transformation of Gregor Samsa from travelling salesman, conscientious breadwinner for a whole family, into an immobilisingly large insect in *Metamorphosis* and Hans Castorp's puzzlingly steady conversion in *The Magic Mountain* from healthy young man, about to make his contribution to society as an engineer, to a lovelorn full-time invalid at a TB sanatorium, Natanson reveals the phenomenological foundations of these works' potency, writing that when "routine existence is halted for some unexpected reason, the weight of its traditional performance crashes through the 'membrane' of consciousness".<sup>421</sup>

Significantly, this crash has a greater impact on the reader or play-goer – still immersed in the normalcy, assumptions and routines of their own life-world - than on the characters, who tend to express instead an almost fatalistic brand of acceptance. About *The Metamorphosis*, surely the story in which the protagonist's fate is least within his agency to correct, Natanson writes: "“What has happened to me?” is never answered in Kafka's story [...] His circumstances have altered. Others have changed”.<sup>422</sup> Nathi, likewise, treats the issue of his HIV-positive status as though it were largely unremarkable: a concern in his life, certainly, but not by default the foremost concern. His circumstances have altered. Other things are changing. The element of surprise produced by the lack of any form of stigma or moralisation in Nathi's narration challenges readers accustomed to expect a particular narrative of HIV/AIDS or illness, one that follows either a tragic or redemptive arc.<sup>423</sup> In *The Reactive*, HIV/AIDS is shown to us

<sup>421</sup> Maurice Natanson, *The Erotic Bird* (1998), p. 124.

<sup>422</sup> Ibid, p. 106.

<sup>423</sup> In *The Wounded Storyteller*, Arthur Frank writes that “no one wants to hear” a chaos narrative, which is the opposite of such redemptive restitution narratives. An analysis of oral histories from Holocaust survivors found that “very subtly, the interviewers direct witnesses towards another narrative that exhibits ‘the resiliency of the human spirit’” (Frank, 1995, p. 101).

through the eyes of Nathi not as a social disaster but a deeply personal event, and we come to comprehend Nathi as (in the least metaphorical sense possible) the agent rather than the victim in that event.

## Conclusion

Ntshanga has cited Albert Camus – another chronicler of epidemic through his novel *La Peste* (1960) - as an influence in his writing, and *The Reactive* could be seen as reflecting the Absurdist's taking of humanity's unfounded compulsion to identify inherent order, value and meaning to their existence as the subject for art. In his manifesto of absurdity 'The Myth of Sisyphus', Camus writes that: "Judging whether life is or is not living amounts to answering the fundamental question of philosophy".<sup>424</sup> For Ntshanga's characters, the question is both ontological and political, as they attempt to assimilate the promise of newly possible ways of living with a reality still tarnished by the past. However, the inverse of recognising the Absurd nature of existence is true existential freedom, and the novel's apparent plotlessness and lack of affect belies the more redemptive outlook realised in its ending. Nathi even expresses an optimistic, exceptionalist view of the HIV/AIDS epidemic in South Africa, wondering if the devastation would produce "a newer, stronger human species, one resistant to a thousand more ailments" and speculating whether "our country [had] been selected in particular for this trial".<sup>425</sup>

<sup>424</sup> Albert Camus, *The myth of Sisyphus*, trans. by Justin O'Brien (London: H. Hamilton, 1965).

<sup>425</sup> *Ibid*, p. 194.

The two generations which Coovadia and Ntshanga represent (incidentally, the former was once the latter's creative writing teacher at the University of Cape Town) could be seen to mirror two generations within the post-Apartheid fiction scene in South Africa so far: the key distinction being between whether the writers experienced the Apartheid years as memory or history. Imraan Coovadia was born in 1970, at a time when the Apartheid regime was intensifying its state-sanctioned surveillance and persecution, and South Africa was becoming increasingly isolated from and ostracised by the international community. Masande Ntshanga – born just 16 years later, in 1986 – would count among his childhood memories the reversal of this process. From the unbanning of the ANC in 1990 to official democratic freedom in 1994, during his formative years South Africa transformed from a pariah state to a 'miracle nation'. Ntshanga's generation of 'Born Frees' were originally criticised for apathy and lack of awareness of the sacrifices and suffering incurred to enable their freedom: of late, this generation has begun to turn the narrative on its head, challenging the extent to which that freedom has been achieved.<sup>426</sup>

Unlike in *Tales of the Metric System*, where the chronological succession of chapters emphasises the inexorable march of change - if not necessarily progress, the prose of *The Reactive* flows loosely between memories, dreams and reality, with the effect that past and present often seem to exist simultaneously. The characters in the former – whether activists, power-holders, writers, or citizens, are often labouring to shape and influence the times they live in. By contrast, for the characters in the latter, the workings of time are something nebulous that can mostly be passively endured: "Time seems to speed up here, and then it

<sup>426</sup> See for example Sipho Mphongo, 'The "Born-Free" Generation', *Anthropology Now*, 8(3), (2016), 95-110. The failure of the new government to deliver substantial change to older generations is also deeply ingrained in the rhetoric of the #FeesMustFall movement, which campaigned for employment reform for cleaners and support staff at higher education institutions along with changes to fee structures and decolonisation of curricula.

stalls, and then it seems to speed up again before it stalls”, Nathi observes of Cape Town (p. 48); at another moment, he realises that “my hours have become something foreign to me, that they’ve taken on a pattern I can no longer predict” (p. 72). Ntshanga, however, exerts a tighter control over the passage of time than his narrator, and *The Reactive* has an understated unity of time and action. In the concluding section, the ANC’s policy reversal on ART provision appears (in a novel otherwise undisturbed by the workings of high politics) as a kind of real world *deus ex machina*:

[T]he South African cabinet had ruled to provide free ARVs to the country's citizens. Most of us were still in disbelief. Sis’ Thobeka, whom I’d called from a pay phone close to work, had held back tears [...] The article said that the government planned to provide treatment for a hundred thousand of us by March the following year. Who knew? I thought. It was enough to believe them for now.<sup>427</sup>

Ntshanga’s protagonist experiences this news in tandem with a personal reprieve. Seemingly on the same day,<sup>428</sup> Nathi is revealed to be the eponymous ‘reactive’ - a person whose HIV cells take longer than average to reproduce. If Coovadia’s novel, with its episodic, chronicling structure, tracks the disappointing consistencies between two enemy regimes, Nathi’s delayed coming-of-age mirrors South Africa’s stumbling, imperfect, but nonetheless semi-miraculous entry into democracy.

<sup>427</sup> Masande Ntshanga, *The Reactive* (2017), pp. 179-180.

<sup>428</sup> When he discovers that his CD4 count has not been diminishing, Nathi goes into town to email his old boss from the laboratory. “It was a Tuesday” (192). He also sends him the link to “a news article about the government’s new Operational Plan [d]ated 1 September” (193), which in 2003 fell on a Monday.

## CHAPTER FIVE – HIV/AIDS AND THE BODY SOCIAL

### IN SOUTH AFRICAN NON-FICTION

The more I heard about Fana Khaba, the more it became clear that this man had lived every twist of the drama that had transformed my country during my long absence.

Liz McGregor, *Khabzela!* (2006)

We were living in the mid-80s, the final years of Apartheid, and our minds were on the body politic, not the human body. We knew dimly that the spread of AIDS had reached pandemic proportions in some African countries thousands of miles to the north of us. We knew too that, unlike in the developed world, it was being transmitted primarily by heterosexual men and women. Yet Cameroon, Uganda and Zaire were faraway places, not only in miles, but in our imaginations. Under Apartheid, South Africans, both black and white, grew to think of ourselves as exceptional Africans, indeed, as exceptional human beings, a hubris the world's fascination with us only quickened.

Jonny Steinberg, *Three Letter Plague* (2009)<sup>429</sup>

During the height of Apartheid control, literary fiction was a crucial medium for bearing witness to and communicating the situation within South Africa to the outside world. In fact, South Africa's stark oppression irrevocably shaped the development of the country's fiction, motivating writers to document and broadcast the dehumanising effects of the apartheid machinery and the resistance of anti-apartheid fighters. Writers such as Alan Paton, Nadine Gordimer, Andre Brink, Es'kia Mphahlele, Lewis Nkosi and J.M. Coetzee became some of the most high-profile international ambassadors for the anti-Apartheid cause, facing severe

<sup>429</sup> Liz McGregor, *Khabzela!* (2014), Location 44, Kindle edition; Jonny Steinberg, *Three Letter Plague*, (2009), p. 333.

censorship and banning within their home country as a result of their work. By the time independence came, the literary critic Njabulo Ndebele felt compelled to intervene in the limitations the protest fiction tradition implied for black South African writers in particular, interrogating how the political history of the country had “enforc[ed], almost with the power of natural law, overt tendentiousness in the artist’s choice of subject matter and [...] a high level of explicit political pre-occupation”.<sup>430</sup> As the shadow of Apartheid conflict lifted, and with it the censorship laws that had prevented many within in the country from writing and publishing, there was not the immediate outpouring of new literary voices that some had anticipated. As Ndebele had identified, it took some time for writers to find new possible modes and styles for writing, not to speak of the plethora of cultural and (infra-)structural delineated in an earlier chapter. This lag was accompanied by a perceptible “shift in literary energy from fiction to non-fiction”, which perhaps presented a more appealing genre for South African intellectuals attempting to capture and understand their new social landscape in the immediate aftermath of Apartheid’s demise.<sup>431</sup> Congruently, texts sought less explicitly to appeal to the moral conscience of those beyond its borders, as internal scrutiny and seeking to make sense of the nation’s condition took on new gravity.

The emergence of the HIV/AIDS epidemic was one of the challenges imbued with especial urgency by non-fiction writers, for whom it had the added benefit of illuminating racial and socio-economic fault-lines of South African society that were still too sensitive easily to trace outright. In the first part of this chapter, I reflect on the ways in which two South African writers took the HIV/AIDS epidemic as their subject in the post-Apartheid moment. In

<sup>430</sup> Njabulo S. Ndebele, *South African Literature and Culture: Rediscovery of the Ordinary* (Manchester: Manchester University Press, 1994), p. 27.

<sup>431</sup> Rob Nixon, ‘Non-Fiction Booms?’ (2012), p. 29.



particular, it suggests that interactions between early non-fiction narratives of HIV/AIDS in South Africa were importantly and consciously intertwined with the developing narrative of the state of the post-Apartheid nation.<sup>432</sup> In their respective books, *Sizwe's Test* (2007), and *Khabzela!* (2006), Jonny Steinberg and Liz McGregor reconnoitre a country that they acknowledge a certain removal from through the subject of the epidemic. Both had spent time away from South Africa – Steinberg pursuing his doctorate at the University of Oxford and McGregor working in journalism in Britain and the United States – returning along with many contemporaries to witness the new era unfold.<sup>433</sup> While these writers' decision to focus on marginalised experiences can be seen as working within “the impress of a powerful scholarly tradition of history from below” that characterised the nation's non-fiction,<sup>434</sup> at the same time, their position as white South Africans who could both physically and psychologically distance themselves from Apartheid's most harmful effects is also important to a critical reading of their narratives.

I suggest that these two texts were produced at an intersection between ethnography and literary craft, within non-fiction's “generic edgelands where documentary forms and fictional strategies mingle and liaise”,<sup>435</sup> and which therefore productively complicate the reader's position vis-à-vis the text's production of knowledge. The resurgence of non-fiction at this

<sup>432</sup> HIV/AIDS formed an ambivalent foil to Apartheid in a narrative sense. The novelist Phaswane Mpe told Lizzy Attree in interview that he engaged the subject in part as an “antidote to those who think that South Africans have nothing to write about in the post-Apartheid context” (Lizzy Attree, ‘Interview with Phaswane Mpe, (2005), p. 42).

<sup>433</sup> Their books can be seen as part of the ‘non-fiction renaissance’: Steinberg in particular, according to Hedley Twidle, has “probably done most to secure the pre-eminence of a kind of non-fiction that may or may not be best described as ‘literary’ or ‘creative’, but is undoubtedly intensively researched, textured, character-driven, self-aware” (Hedley Twidle, ‘In A Country Where You Couldn't Make This Shit Up? (2012), p. 6).

<sup>434</sup> Rob Nixon, ‘Non-Fiction Booms?’ (2012), p. 30.

<sup>435</sup> Ibid, p. 33.

historical moment in South Africa may be seen as evolving from the emphasis on political and social realism that characterises literary fiction and poetry produced during the Apartheid era, a time which Lewis Nkosi memorably described as filled with more implausible lived realities than anything an Absurdist playwright or novelist could conjure up. In such a social context, critics argued, fiction for fiction's sake would be "the almost deliberate waste of intellectual energy on trivialities".<sup>436</sup> As literary fiction borrowed from the descriptive, journalistic qualities traditionally associated with non-fiction, its evocative and imaginative aspect seemed to seep into the latter, which became "to an unprecedented degree, an attractive genre for many of the nation's most inventive writers [so that] the form assumed greater institutional respectability while accruing a fan base that no longer treats it as extra-literary".<sup>437</sup>

Another underlying rationale for the fresh prominence of non-fiction might be the heightened need for authors' sensitivity towards the politics of representation, in the wake of a regime which had for generations illegalized the majority's right to self-expression. While the two authors under discussion here are by birth South African, their texts' claims to speak about and for Sizwe and Fana Khaba, their communities, and South Africa as a whole, inevitably bear traces of the ethnographic approach. The experiential divide produced by decades of segregation produces a qualitatively anthropological approach to the subjects' stories, in that the authors can hardly expect otherwise than to encounter limits to their understanding. McGregor emphasises how the laws of the country under Apartheid imposed physical separation between black and white South Africa life: "as a young reporter in the eighties I

<sup>436</sup> Njabulo Ndebele, *South African Literature and Culture* (1994). p. 42.

<sup>437</sup> Rob Nixon, 'Non-Fiction Booms?' (2013), p. 30.

had passionately identified with the liberation struggle [but] as a white person I entered black townships rarely and fleetingly”.<sup>438</sup> Steinberg, describing his process of writing *Three Letter Plague* in an email interview with Lizzy Attree, wrote “I cannot do the one thing that gives modern fiction its signature: I cannot drift in and out of the thoughts of anyone except myself”.<sup>439</sup> The tensions and distrust that linger in post-Apartheid South Africa make the endeavour of identifying universal human experiences particularly fraught, and the writers’ wariness of claiming to fully speak for their subjects paradoxically hinders them from deviating completely from the Eurocentric template in which Mbembe notes that the African “belongs, up to a point, to a world we cannot penetrate”.<sup>440</sup>

As a discipline, anthropology is engaged not only in understanding cultural worlds but in explaining them, i.e. translating them into theoretical language. This process involves turning a ‘small’ story into a ‘large’ one, imbuing the anecdote of a single encountered life with connotations of certainty. (Didier Fassin pinpoints the “specificity” of ethnography, in contrast to history or writing in general, as a useful tool “to apprehend the life of others and make use of their ideas and actions”).<sup>441</sup> In both *Khabzela!* and *Three Letter Plague*, the authors trace the lives of two black South African men, the former set within the urban environments of Soweto and Johannesburg and the latter, a rural, isolated village in the Eastern Cape province that Steinberg calls Ithanga. Their individual stories are presented as paradigmatic of a wider truth, which is signalled in the titling or marketing of the books: Liz McGregor’s biography of the late radio personality Fana Khaba, who was known popularly

<sup>438</sup> Liz McGregor, *Khabzela!* (2014), Location 40, Kindle edition.

<sup>439</sup> Lizzy Attree, *Blood on the Page* (2010), p. 166. Debate about the prerogative of fiction writers to write the subjectivity of ‘Others’ has become a keen and contested issue within the literary world at present, as part of a wider reckoning with practices of cultural appropriation.

<sup>440</sup> Achille Mbembe, *On the Postcolony* (2001), p. 2.

<sup>441</sup> Didier Fassin, ‘A case for ethnography’ (2013), p. 22.

as Khabzela, is subtitled *The Life and Times of a South African* (2006), while *Three Letter Plague* was originally published in South Africa under the title *Sizwe's Test: A Young Man's Journey Through a Great Epidemic*. Steinberg describes his 'character' as an Everyman, whose pseudonym 'Sizwe' (which means "nation" in isiXhosa has undeniably allegorical undertones.<sup>442</sup> In repurposing Sizwe and Khabzela as incarnations of South African society, the reader is given an individual through which the mind-boggling epidemic can be grasped at a human level. However, at the same time, the complexity of HIV/AIDS is compacted into a single life story, which must inevitably represent a partial perspective. As Steinberg acknowledges:

There is no particular reason why Hermann Reuter [the MSF doctor] should stand as an emblem of the quest to heal a country of AIDS. Nor is there a special reason Sizwe's response should reflect that of ordinary people across South Africa. But these are the people I have found through whom to tell a story of AIDS treatment, and it is hard to stop myself from thinking of them allegorically.<sup>443</sup>

The metaphor of the 'Everyman' originated as a gender-neutral designation for humanity, but its universalising use through time has tended to reflect a male-centred world view. It is through the subliminal presence of this tradition that the two male figures of Sizwe and Khabzela can so easily stand in for the average South African. Yet these narratives thus consign to the background the ways in which South African women have experienced, have been affected by and have navigated HIV/AIDS. This is a hugely important omission, given that women in South Africa are disproportionately affected by the epidemic. HIV prevalence among young women (aged between 15 and 24) is nearly four times higher than that of men

<sup>442</sup> Although 'Sizwe', not Steinberg, chose the name by which he is referred during the book, the title can nevertheless be read with an underlying double entendre: 'the test of the nation.'

<sup>443</sup> Jonny Steinberg, *Three Letter Plague* (2009), pp. 371-372.

their age, a group that made up 37% of new infections in the country in 2016.<sup>444</sup> Although South African women living with HIV/AIDS feature in both books, they take on relevance to the narrative as partners or mothers, not protagonists. Later in this chapter I explore Steinberg's own reflections, in a 2016 article, on how a greater prioritisation of the experiences and actions of Ithanga's women may have produced a different narrative.<sup>445</sup>

The tendency to tell the HIV/AIDS story through the male perspective made it significantly more difficult to source South African texts which foreground the gender implications of the epidemic (indeed, all of the texts discussed in previous chapters also feature male protagonists). It is hoped that later research will balance this; at this stage I offer a brief discussion of a recent addition to this canon which also casts the (female) protagonist as a telling emblem of South African society. The journalist Redi Thlabi's *Khwezi: The Remarkable Story Of Fezekile Ntsukela Kuzwayo* (2017) is a sympathetic biography of the woman who accused Jacob Zuma of rape in 2005, in the case which prompted Zuma's problematic statement that he had taken precautions to avoid being infected with HIV by taking a shower. 'Khwezi', a pseudonym used for protection, was revealed after her 2016 death as Fezekile Ntsukela Kuzwayo, an AIDS activist and daughter of Judson Kuzwayo, a MK leader during the anti-Apartheid struggle. For Thlabi, Kuzwayo's life reveals "a society that had allowed the erasure of a young woman's presence".<sup>446</sup>

<sup>444</sup> The most recent *National Strategic HIV Plan* (date) has centred its approach to HIV prevention around interrupting this cycle. In 2016, the government launched a national campaign to try and improve these health outcomes for women. The 'She Conquers' campaign focused on decreasing teenage pregnancies, preventing gender-based violence, keeping girls in school, and increasing economic opportunities for young women, which are considered co-factors in the high levels of HIV transmission.

<sup>445</sup> Jonny Steinberg, 'Re-examining the Early Years of ART in South Africa', (2016).

<sup>446</sup> Redi Thlabi, *Khwezi: The remarkable story of Fezekile Ntsukela Kuzwayo* (Johannesburg: Jonathan Ball, 2017).

## Ethnographies of treatment as national story-telling

Both the authors of *Khabzela!* and *Three Letter Plague* seek to answer the question: Why did (and do) South African people who could access treatment choose not to? After its citizens had struggled for so long and so hard to create a liberated South Africa, and subsequently for their government to provide antiretroviral treatment, they puzzle, why would they give up their lives now at such an apparently surmountable hurdle? In *Khabzela!*, McGregor interviews those who were around Fana Khaba before his death, including people in the alternative healing community like Tine van der Maas whom she considers complicit in directing Khaba away from the ARV programme he had initially begun.<sup>447</sup> She describes the purpose of her book thus: “to understand the central paradox of his death – why he refused the drugs that might have saved him”.<sup>448</sup> In his preface to *Three Letter Plague*, meanwhile, Steinberg writes that the idea for writing the book came from the publication of Justice Edwin Cameron’s memoir *Witness to AIDS* (2005), in which Cameron recounts the momentous decision by Botswana’s government to provide free antiretroviral treatment to all its citizens who needed it in 2002. The Botswanan policy was “unprecedented in sub-Saharan Africa” and well-publicised to the country’s population in advance.<sup>449</sup> However, two years after its launch, less than 15% of those eligible had claimed the free treatment, the rest neglecting its potential to maintain their health in an apparent bid to avoid the stigma of

<sup>447</sup> Rather fascinatingly, the book’s single review on Google Books takes issue with McGregor’s perspective, showing the epistemic struggle over the treatment issue to be ongoing: “I really don’t understand why the writer does not support Tine Van Der Maas. I’m sure that the writer (sic) knows nothing about the real healing program of Tine Van Der Maas. People must judge by themselves (sic) and must not believe in a book. Words are less powerful than the real reality. There are a lot of videos on <http://www.tinevandermaas.com/video-clips/> that are more useful than (sic) this book. The pharmaceutical (sic) mafia is here. But everyone knows that natural remedies are safer than? chemical and hazardous treatments (just have a look at the boxes for ARVs !!!)”.

<sup>448</sup> Liz McGregor, *Khabzela!* (2014), Location 45, Kindle edition.

<sup>449</sup> Jonny Steinberg, *Three Letter Plague* (2009), p. 1.

AIDS.<sup>450</sup> Steinberg calls this story “ghastly” and opened the book by asking, semi-rhetorically: “Does this foreshadow an entire region’s response to AIDS?”<sup>451</sup>

I have examined how the identification of the epidemic with the nation found expression through the figure of Thabo Mbeki, who was alternately seen as stymieing South Africa’s progress in tackling the epidemic and as representative of a general internalised resistance towards the imported treatment technologies. In *Three Letter Plague*, Steinberg attributes Mbeki’s objections to a prevailing “bitterness” against the West (an argument that builds on Fassin’s economy of suspicion and resentment) and distils this national disposition back down to one – this time ordinary – individual:

Rage like Mbeki’s is all over Lusikisiki [...] The accusations expressed in national politics are also stitched into village life, and, indeed, into individual consciousness. On one level, this book is an exploration of the place of blame and resentment in one man’s decision whether to test his blood for HIV.<sup>452</sup>

When they first meet, Sizwe tells the newcomer Steinberg that, “I am scared to test. I think I will test positive”.<sup>453</sup> Steinberg is “taken aback by what appeared either to be a confessional outburst or a moment of exhibitionism” and asks Sizwe for permission to make him a subject in his book.<sup>454</sup> This encounter was undoubtedly serendipitous: Sizwe presented himself as a perfect subject not only in his forthcoming personality, but also as a man who expediently

<sup>450</sup> Bagele Chilisa’s article ‘Educational research within postcolonial Africa: a critique of HIV/AIDS research in Botswana’ (2005), discussed earlier in this study, offers a possible counter-narrative to the (Afro)pessimism inspired by these statistics.

<sup>451</sup> Jonny Steinberg, *Three Letter Plague* (2009), p. 1.

<sup>452</sup> Ibid, pp. 7-8.

<sup>453</sup> Ibid, p. 17.

<sup>454</sup> Jonny Steinberg, *Three Letter Plague* (2009), p. 17.

embodies the region's predicted lacklustre response to AIDS. In order to answer his research question, Steinberg had sought out a "place where poor villagers lived within walking distance of well-administered drugs [...] I wanted to go there and find people who were staying home and dying, and I wanted to know why".<sup>455</sup> Although ART was not within walking distance for all of the inhabitants of Sizwe's village, the foreign NGO *Médecins Sans Frontières* (MSF) had established itself there and was providing "decent AIDS treatment", in partnership with the Eastern Cape Department of Health, through "the district's rickety and neglected primary health-care clinics".<sup>456</sup>

As mentioned, Steinberg describes the person around whom he has constructed his narrative in *Three Letter Plague* as an 'Everyman'. An 'Everyman' character traditionally signifies an ordinary individual with whom an audience or reader can easily identify and imagine themselves navigating and reacting to extraordinary circumstances in a similar way. 'Sizwe Magadla' (a pseudonym) is a young man with a girlfriend and a baby on the way, and the enterprising owner of a spaza shop (the South African term for a convenience store). This last fact marks him as extraordinary – almost an outsider- within the small village that Steinberg dubs Ithanga, in which unemployment is high, and most of his peers are "sullen young men idling dangerously through empty time [...] souls with unknowable futures".<sup>457</sup> However, he remains ordinary enough for the purposes of the narrative in the sense that he was "healthy and strong and had never tested for HIV, which puts him in a category shared by most South African men his age".<sup>458</sup>

<sup>455</sup> Ibid, p. 3.

<sup>456</sup> Ibid, p. 3.

<sup>457</sup> Ibid, p. 14.

<sup>458</sup> Jonny Steinberg, *Three Letter Plague* (2009), p. 8.



Fana Khaba, who came to fame under the moniker DJ Khabzela, was also both an Everyman and an outlier – his life story is a rags-to-riches journey, from an impoverished upbringing blighted by Apartheid oppression in Soweto, to iconic and affluent radio celebrity. Khabzela became the most popular DJ on Yfm, a station broadcasting to young people in the Johannesburg area, and one of the first to shape the medium after the post-Apartheid deregulation of the airwaves.<sup>459</sup> Khabzela’s show reached the new so-called ‘Y’ or ‘kwaito’ generation, and his announcement of his HIV positive diagnosis on air made a significant impact on opening up the AIDS discourse in South Africa. However, Khaba ultimately elected not to follow an ART regimen and passed away in 2004. Just as Steinberg selected Sizwe as a fitting life through which to tell the story he wanted to tell, one that contradicts the story that “human lives are [...] the sites of blunt, blind tragedy”,<sup>460</sup> McGregor is drawn to Khaba for what he is seen to symbolise. In the quote used as an epigraph to this chapter, McGregor suggests that Khaba’s life story imitates the transformation of South Africa, from disenfranchisement to triumphant liberation through to the unforeseen disaster of HIV/AIDS. In his rejection of ARVs in favour of unproven remedies such as ‘Africa’s Solution’, a vitamin tonic developed by an Afrikaner biochemist that has been marketed as effective in decreasing the viral loads of PLWHA, Khaba presents the country’s apparently self-sabotaging approach to HIV/AIDS in microcosm.

<sup>459</sup> Under Apartheid, the South African Broadcasting Corporation (SABC) actively used censorship to maintain the state ideology, with a mandate to guard against subversive content that became more severe in moments of particular political volatility. While in keeping with the policy of ‘separate development’, the SABC did have black radio stations, it was also beholden to the agenda of the state, resulting in “anodyne, formula-bound styles” of music. “Those who remembered the previous era coined a derogatory term for the bouncy new popular music, mass-produced by the stations with the help of able but guileless musicians from the countryside: they called it *msakazo* (broadcast)” (Christopher Ballantine, *Marabi Nights: Jazz, ‘Race’ and Society in Early Apartheid South Africa* (Johannesburg: Raven Press, 2013), p. 11). Yfm and Khabzela were, in stark contrast, champions of the new township genre of *kwaito*, which draws on elements of house music, African dance beats and hip hop, and was associated with political freedom due to both anti-Apartheid lyrics and its expressive, exuberant and authentically South African sound.

<sup>460</sup> Jonny Steinberg, *Three Letter Plague* (2009), p. 2.

As a public personality, Khaba was (like Mbeki) already in many ways a figure whose meaning was overdetermined and available for projections. At his funeral in Orlando stadium, McGregor is shocked by how the various speakers “tried to harness him to their particular cause”,<sup>461</sup> be that AIDS activism and campaigning for ARV treatment, electoral registration (and voting ANC), or Christian messages around chastity:

The fact that Fana was apolitical, didn’t believe in ARVs and had sex with hundreds of women he wasn’t married to appeared to be irrelevant to his alleged eulogisers. It was his brand that was important and that could be appropriated by anyone now. Forever silent, he couldn’t contradict any of the claims made on his behalf.<sup>462</sup>

McGregor herself describes her first encounter with her subject in rather acquisitive terms: she recalls that while working as a freelance journalist, an American publication was looking for stories about HIV positive celebrities: “[i]n South Africa in 2003, black celebrities living openly with HIV were pretty thin on the ground so when Yfm DJ Khabzela announced on air one day that he was HIV positive, I pricked up my ears”.<sup>463</sup> After interviewing Khabzela for the magazine, she is intrigued to follow the story further. As Khabzela passes away not long after they meet for the first time, however, the biography is constructed through a combination of research and interviews with people to whom Khaba was connected, much of which are relayed through large sections of verbatim. Steinberg similarly collects stories from a variety of people, although with Sizwe more than anyone else, in an effort to understand

<sup>461</sup> Liz McGregor, *Khabzela!* (2014), Location 236, Kindle edition.

<sup>462</sup> Ibid, Location 256.

<sup>463</sup> Liz McGregor, *Khabzela!* (2014), Location 31, Kindle edition. It is worth noting, particularly in relation to the discussion in the previous chapter, that “[a]lthough a majority of illness narratives are written by authors with no great literary or commercial aspirations, celebrity remains the most important determinants of an illness narrative’s commercial success” (Neil Vickers, ‘Illness Narratives’ (2016), p. 389). One reason is that juxtaposition of the social cachet and glamour of celebrity with the vulnerability produced by illness produces a fascinating duality between power and powerlessness. By comparison, illness narratives written by or about people who are already coded as suffering perhaps have less inherent attraction to publishers or book buyers.

both the state of treatment provision and the unspoken antagonism towards the treatment, or what it represents. These conversations are often related as dialogue, accompanied with Steinberg's commentary on both what Sizwe says and what he perceives to go unsaid. Sometimes the use of free indirect speech also blurs the difference between what Sizwe directly expresses, and what Steinberg interprets from his utterances, as in for example: "Embodied in the vocabulary of this language [English], he thinks, is a force of great corrosive power, one that has been eating away at the substance of his family since his grandfather's times".<sup>464</sup>

This particular observation also speaks to epistemic tensions in the narrative, revealed most tellingly by areas of shared ground. (Close to the end of the book, Steinberg also reveals personal, deeply emotional experiences around HIV testing, and although this connection was somewhat subconscious during the course of his writing the book, he "knew in the back of [his] mind that my own experience of AIDS prefigured Sizwe's in ways that were astoundingly obvious").<sup>465</sup> Although Steinberg speaks a little isiXhosa, the majority of their communications are in English, a language which Sizwe speaks well but apparently has misgivings towards. Often the most interesting moments between the two men are therefore when fundamental discursive divisions between their realms of experience come to the surface:

'It is a disgrace to be HIV-positive'.

'Why?'

<sup>464</sup> Jonny Steinberg, *Three Letter Plague* (2009), pp. 20-21.

<sup>465</sup> Jonny Steinberg, *Three Letter Plague* (2009), p. 332.

We were walking from his father's place to his shop. He stopped in his tracks and glanced at me anxiously. The look in his face was one of acute embarrassment, as if he and his entire milieu had been caught doing something shameful and nasty.

'Is it not a disgrace where you come from?'<sup>466</sup>

Sizwe appears startled to think that the village's reaction of fear and confusion is not universal, and is subsequently relieved when Steinberg assures him that the epidemic provoked similar responses all over the world. Initially, however, he exhibits feelings of anxiety, embarrassment and shame at the thought that the reaction is symptomatic of their seclusion from modernity. For Sizwe, who has lived his whole life in the village in which he was born, access to new knowledges often comes via outside sources, which are carefully and privately weighed against his own. (It is not entirely clear whether Sizwe's "where you come from", in reference to Steinberg, signifies Johannesburg or a wider - perhaps more abstract - location). In other words, Steinberg's meaning-making through Sizwe is filtered through his subject's simultaneous projection of meaning. Both South Africans, they 'come from' different epistemic standpoints that in meeting, produce a third, intermediate space of shared misunderstanding. To some extent this space is the object of analysis throughout this study.

While Thabo Mbeki was in a position that enabled him not only to respond but also to shape the extraordinary circumstances produced by the HIV/AIDS epidemic on a national scale, the agency of the 'characters' of Sizwe and Khabzela is largely limited to their own bodies and lives. Where Mbeki has been described as a victim of what Miranda Fricker terms testimonial injustice, the latter can be seen as victims of hermeneutical injustice. As outlined previously, the former designates a person's inability to communicate knowledge in a way that will be

<sup>466</sup> Ibid, p. 35.

received. Mbeki's controversial stance, as has been seen, was entrenched by his perception that he was being deliberately misunderstood. Hermeneutical injustice, meanwhile, refers to a lack of collective interpretive resources which actors can use to advocate for their own needs. Steinberg's observation of Sizwe's reliance on English as a "weapon" that he knows will help him meet the wider world outside Ithanga "appropriately armed",<sup>467</sup> co-existing with a serious belief on some level that it is harmful to his people's souls, provides us some intimation of how much more could be done to make ART not only a physically but an epistemically accessible resource.

McGregor meanwhile writes towards the end of *Khabzela* that she was excited to discover that Khaba had had a consultation with Dr David Spencer, "one of the most highly regarded HIV clinicians in the country".<sup>468</sup> The chapter title, 'A Decent Doctor Spurned', makes clear her stance on Khaba's failure to take advantage of this opportunity (their consultation lasted only a minute, after Spencer told Khaba he would not use herbs to treat him). For McGregor, the answer for what a responsible individual ought to do is so obvious that the option to choose is irrelevant: "HIV can be avoided by a change in sexual behaviour. If contracted, it can be controlled with the correct treatment",<sup>469</sup> i.e. the anti-retroviral drugs that Dr Spencer could have offered Khaba. What this omits, however, is that how McGregor and Spencer's worldview's alignment with Western medicine and healthcare practice produces an easy sense of trust in ARVs that is not universal. Khaba is epistemically disadvantaged in that his choice is not a clear-cut one between life and death, but between a treatment plan that

<sup>467</sup> Jonny Steinberg, *Three Letter Plague*, p. 20.

<sup>468</sup> Liz McGregor, *Khabzela!* (2014), Location 2484, Kindle edition.

<sup>469</sup> Liz McGregor, *Khabzela!* (2014), Location 101, Kindle edition.

violates his cultural autonomy and beliefs (for example, as a lifelong Jehovah's Witness, he refuses to receive a blood transfusion), and one which does not.

David Dickinson has recently argued that “the Great AIDS dispute was a dispute between elite groups”,<sup>470</sup> indicating that while certain elements of Mbeki's objections are recognisable in ‘grassroots’ opinions about HIV/AIDS, most research accounts tend to dismiss the bulk of non-elite knowledges about the disease, no matter how popularly believed. In both of these texts, we can identify this underlying disconnect between the authorial perspective and that of many of the subjects. In *Khabzela!* McGregor describes how out of all the rival healers that Khaba encountered as he battled the virus, he placed the most trust in ‘Dr Irene’, who while “equated in their minds with ... white Western medicine ... also brought in divine agency and emotion, which Western medical practitioners fail to do”.<sup>471</sup> Because the storytelling aspect of indigenous health practices (as emphasised by Phaswane Mpe) cannot comfortably co-exist with Western medicine's definition of rationality, the therapeutic potential of the former was in most cases sacrificed to preserve the latter.

True belief in indigenous health systems effectively forms a hidden transcript of the discourse about HIV/AIDS in South Africa. Given that a significant swathe of the population invests trust in these systems, there is still a huge lack of texts exploring traditional health practitioners' treatment of HIV/AIDS.<sup>472</sup> The authors' ethnographic interest in the

<sup>470</sup> David Dickinson, *A Different Kind of AIDS* (2014), p. 288.

<sup>471</sup> Liz McGregor, *Khabzela!* (2014), Location 2017, Kindle edition.

<sup>472</sup> See Thembelihle Zuma et al, ‘Traditional health practitioners' management of HIV/AIDS in rural South Africa in the era of widespread antiretroviral therapy’, *Global Health Action*, 10(1), (2017) for a useful summary of background literature on the topic. N.B. Traditionally the ceremonies by which people who have the ‘calling’ are inducted into healing are veiled in a certain amount of secrecy, which is a significant factor in the amount of research and published knowledge.

significations of anti-retroviral treatment inevitably brings South African indigenous forms of healthcare into their narratives. In fact, Steinberg initially comes into contact with Sizwe “because I hoped to meet his father [...] I had put out word that I wanted to get to know an *igqira*, a diviner-healer”.<sup>473</sup> However, alternative treatments and paradigms remain mostly foils to the protagonist of ART, and do not quite come into focus in their own right.

### **Rival healthcare knowledges**

The postcolonial scholar Maria Paula G. Meneses notes that “today, most analyses begin by presenting modern knowledge systems – such as biomedicine – as globalized forms of knowledge”.<sup>474</sup> Earlier chapters have discussed how biomedical accounts have been established not only as the dominant explanation for HIV/AIDS but imbued with a dogmatic quality, so that others become practicably unspeakable. In the South African context there were two sets of alternative paradigms at work. The first is the process by which ‘dissident’ AIDS theories are, once proved to be without empirical value, removed from the scientific canon. (Hereafter, they continue to exist as texts, but not necessarily as scientific ones). The second is how the non-biomedical health systems suffer an epistemic disadvantage in relation to other conceptions of medicine. Meneses describes how indigenous paradigms of health are marginalised in ways which mirror the marginalisation of the people who use them:

<sup>473</sup> Jonny Steinberg, *Three Letter Plague* (2009), p.13

N.B. *Igqira* (plural: *amagqira*) is the isiXhosa word for a diviner-healer. Another word used throughout South Africa, originally from isiZulu, is *isangoma* (plural: *izangoma*). An *inyanga* (plural: *iinyanga*) is a herbalist, who can offer knowledge of the medicinal qualities of plants but does not, like *amagqira* or *izangoma*, communicate with ancestors in the spirit-world in order to interpret the cause of illness.

<sup>474</sup> Maria P. Meneses, p. 353.

the act of situating the “other’s” knowledge becomes the key moment in the production of a relationship of inequality; from this standpoint, pre-modern forms of healthcare are characterized, *en bloc*, as traditional therapies, frequently of only local relevance.<sup>475</sup>

From a Eurocentric perspective, the characterisation of rival healthcare knowledges as ‘traditional’ and culture-bound thus “reinforc[es] the object status of those who produce it”.<sup>476</sup>

In the context of HIV/AIDS belief in indigenous healing is relegated to the same epistemic standard as conspiracy theories: both are subscribed as superstitious, ill-informed and best suppressed or ignored.

Constructions of South African health-seeking practices which do not include ART (such as taking one’s relatives to a sangoma or igqirha) appear (if at all) almost as an oxymoron within the dominant discourse. Actions of this kind are often received with admonishment or bewilderment, as though the persons involved are deliberately avoiding, rather than seeking, health (McGregor describes Khaba as on “a roller coaster to self-destruction”).<sup>477</sup> However, these chasms between the consciousnesses of the white liberal writers and the subjects of their texts offer an insight into the problem. For many South Africans, centuries in which bodies have been abused within the public health system, sometimes under force and sometimes under false pretences, have created what Didier Fassin (2007) famously called ‘bodies that remember’. Therefore, even though conspiracy theories around AIDS exist via the medium of imagination, they represent a near-tangible sedimentation of empirical evidence, accumulated from a community’s lived experience of and encounters with history.

<sup>475</sup> Maria P. Meneses, p. 353.

<sup>476</sup> Ibid, p. 355.

<sup>477</sup> Liz McGregor, *Khabzela!* (2014), Location 85, Kindle edition.



What Dickinson calls the human rights/treatment paradigm is often taken uncritically as default by writers of HIV/AIDS social history: when McGregor begins her research, for example, she is shocked to discover that other paradigms are taken seriously: “I had assumed that my perception of AIDS was a universal one [...] This conversation [...] was my first indication that the understanding of AIDS could be entirely different”.<sup>478</sup> In the conversation which McGregor refers to as her first inkling of alternative understandings of AIDS epidemiology, Khabzela’s driver Satch tells her,

On that first trip to Fana [...] in a speculative way, as if trying out his theory on me:

‘A man told me that Aids was manufactured by a man named Apollo. He injected it into black people or into things they eat, like oranges. They wanted to kill black people’.

I said I didn’t think that was true; that the generally accepted understanding of the origin of Aids was that humans had caught it from eating monkeys in central Africa.<sup>479</sup>

McGregor takes Satch’s words as unfortunate, indeed tragic evidence of his miseducation; she takes the opportunity to correct him with what she believes to be the “true” story (although she remembers that he merely “listens politely” before continuing with his own). Notable here are the different levels of veracity that are described. Both McGregor’s and Satch’s understanding of the events is garnered second-hand, from sources external to them – one direct, and the other indirect - and their faith in the account they subscribe to reflects the limits of *both* interlocutors’ epistemic perspectives. McGregor describes her understanding as the “generally accepted” one, but this invoked general majority is coded white and western and juxtaposed to local ‘theories’, even as the understanding itself is probably garnered from

<sup>478</sup> Liz McGregor, *Khabzela!* (2014), Locations 96, 102.

<sup>479</sup> Liz McGregor, *Khabzela!* (2014), Location 84, Kindle edition.

media representations and filterings of biomedical research rather than from specialist publications.

Inhabiting an assumed position of one bringing expertise and objective information, McGregor therefore interprets the “speculative” tone of Satch as a request for verification, which she denies. However, one could also interpret the scene in another way, with Satch taking the first opportunity in which they are alone together to probe whether McGregor might acknowledge the *felt*, even partial, truth within the interpretation that “[t]hey have a cure in New York but they want lots of black people to die first”.<sup>480</sup> The historian Luise White has noted that hearsay and rumour can become a reliable source of information in as far as they “can resolve some of the confusions that are contained in experience”.<sup>481</sup> In some ways, this incident could be read as an epistemic test of an unknown outsider: McGregor’s haughty response marks her as on the wrong side of James Scott’s *cordon sanitaire* between the powerful and powerless, and thus not a person within the community to whom the hidden transcript can be safely revealed, nor one who has earned the right to hear it.

In the course of researching *Three Letter Plague*, Steinberg has similar experiences in which people relate alternative AIDS theories to him, “always unsolicited”, including the same image of AIDS being spread through an injection and through oranges.<sup>482</sup> The HIV-laced needle is attributed here not to the anecdotal figure of Apollo but to Hermann Reuter, the MSF doctor who had moved to Luskisiki in order to establish a treatment programme there. Steinberg discovers that this particular hidden transcript exists barely below the surface:

<sup>480</sup> Liz McGregor, *Khabzela!* (2014), Location 93, Kindle edition.

<sup>481</sup> Luise White, *Speaking with Vampires: rumour and history in East and Central Africa* (Berkeley: University of California Press, 1998), p. 34.

<sup>482</sup> Jonny Steinberg, *Three Letter Plague*, p. 167.

After hearing the AIDS needle story, I began searching the literature on Pondoland for episodes in its medical history. I was seeking echoes of the fear of Hermann Reuter's needle. I stumbled only upon my own ignorance; the echoes were almost everywhere, spanning the generations.<sup>483</sup>

As this shared epistemic resource of rumour is revealed to the authors, another side to their own being-in-the-world is also revealed. Steinberg is, like McGregor, at first taken aback by the rumour that AIDS is being inflicted on black people by white people; however, he soon finds that the idea merely lay beyond his old epistemic terrain. In fact, as implied by the fact that both McGregor, in the township Soweto, and Steinberg, in a hamlet in the Eastern Cape, were told almost identical narratives, the association between public health measures and harm to indigenous Africans ran long and painfully deep: as he writes, "[t]he needle that penetrates African skin to extract or inject substances into African blood has never been a neutral technology; it is an image that has always been hungry for meaning".<sup>484</sup>

Steinberg's longer and closer relationship with Sizwe (Khaba passes away shortly after McGregor meets him for the first time, and unlike Steinberg she does not live in proximity with her interview subjects during her research period) permits him greater insight into the epistemic bounds of his positionality: the transcript hidden from him on account of his identity. On a municipal election day, Steinberg is far from his home ward, and, prioritising his work project, chooses not to vote and instead to accompany Sizwe to the polling station that had been set up at a local school. He registers a look of disapproval on Sizwe's face and then others along the way, so that by the time they reach the school,

<sup>483</sup> Ibid, p. 169.

<sup>484</sup> Jonny Steinberg, *Three Letter Plague* (2009), p. 170.

I had the sense that my relationship with this entire village had been recalibrated. [...] That I was white and not voting, and they black and en route to the school to cast their ballots, re-established the meaning of who I was. I felt the presence of ‘black people’s secrets’, as Sizwe once put it, darting between the polite and masked faces around me.<sup>485</sup>

In *Domination and the Arts of Resistance*, James Scott frequently links the animation of the hidden transcript to ‘masks’, often literal as in when masked peasants at a carnival deliver – benefitting from the relative impunity of anonymity - a “cryptic but threatening” message to the watching noblemen.<sup>486</sup> However, he also establishes its figurative resonance, in the sense of compound subjectivity that is invoked by Steinberg here and has been availed by thinkers such as Friedrich Nietzsche and Frantz Fanon.<sup>487</sup> The “masked faces” of those in power-laden situations is, as Steinberg himself realises, reflective of their alertness towards the power imbalance. Scott writes that: “the more menacing the power, the thicker the mask”.<sup>488</sup> In this scenario, Steinberg does not represent an immediate threat, but he has been demoted from a known entity -Sizwe’s companion - to an alien and thus untrustworthy one: a symbol of the not-so-distant past of tyranny. Voting in South Africa (which at the point when Steinberg is writing means among the black population, almost unanimously voting for the ANC) is still a relatively new universal right and therefore is not taken lightly. It is a ritual loaded with the moral weight of sacrifice and struggle, and an opportunity to express to the rest of South

<sup>485</sup> Jonny Steinberg, *Three Letter Plague*, p. 187.

<sup>486</sup> James Scott, *Domination and the Arts of Resistance*, p. 139.

<sup>487</sup> Friedrich Nietzsche, *Beyond Good and Evil*, trans. by R. J. Hollingdale (London: Penguin Books, 1990 (1886)); Frantz Fanon, *Black Skins White Masks*, trans. by Charles Lam Markman (London: Pluto Press, 2017 (1952)).

<sup>488</sup> James Scott, *Domination and the Arts of Resistance*, p. 3.

Africa – if not the world - the direction which the young democratic nation ought to take.<sup>489</sup>

By treating his vote so casually, Steinberg unheedingly brings to the villagers' attention that he has power that they do not: the privilege of detachment from the country's future, or the entitlement of knowing that his existence does not hinge on the ideological tenor of one party or another. Close to the end of the book, Steinberg writes in what is presented as a channelling of Sizwe's thoughts ("This is what he was saying when he likened himself to the stooge Botha Sigcau"):

You do not sell your interior to whites, for what is inside you is an instance of a shared, black interior. What you are offering to the white man is not yours, it is everybody's: a collective sphere of privacy bounded by race and politics. You do not hawk a piece of that interior to people who have spent generations trying to extinguish your spirit.<sup>490</sup>

While Steinberg and McGregor set out to discover certain truths about the effects of HIV/AIDS on the body social of a country that is both theirs and foreign to them, my reading of both texts reveals ways in which these narratives also depict certain epistemic fault-lines that are often submerged. Although the authors are, to greater and lesser extents, aware of these lines, the blurred edges between ethnographic research and literary craft, between directly reported text and imagined or recreated thoughts, complicate the reader's position vis-à-vis the text's production of knowledge. As African, black knowledges and healthcare beliefs are situated as the unknown element, and therefore the other, the reader is implicitly placed in an epistemic position that is juxtaposed against that of the texts' subjects (Sizwe,

<sup>489</sup> Black voters had been barred from national elections since 1936, when the Hertzog government enacted the Representation of Natives Act, creating separate voters' rolls for the Bantustan legislatures. Coloured voters were subsequently similarly segregated in 1951 with the National Party's Separate Representation of Voters Act. Anthony O'Brien records how the 'electoral sublime' of the first free elections on 27 April 1994 inspired the country's writers, who found in the image of a desegregated, equitably ordered queue "a metonym of national community" (Anthony O'Brien, *Against Normalization* (2001), p. 15).

<sup>490</sup> Jonny Steinberg, *Three Letter Plague*, p. 355.

Khaba and their communities). As such, the texts also present an interesting record of this post-Apartheid moment, as groups previously kept forcibly apart begin to interact with one another's epistemic worlds.

## **Epistemic Gender Trouble**

In September 2016, Steinberg published an article in *African Affairs* journal, revising his initial impression of the ethnographic data that he had used to shape the narrative in *Three Letter Plague*. Referring to how his own book and Didier Fassin's monograph *When Bodies Remember* both centre on themes of fear, resentment and suspicion, he writes, "there was clearly much else going on: feelings, languages and emerging practices that both Fassin and I observed, but to which we do not give sufficient analytic due".<sup>491</sup> While the two studies had plenty of reason to highlight the conflicts around AIDS and treatment that were current in the country and beyond, Steinberg suggests that the focus on negative feelings tended towards an Afropessimistic outlook, failing to anticipate or imagine the present of today, in which more than three million South Africans are successfully receiving ART from state-run clinics. He emphasises that he "was not alone" in this assessment, referencing the books of Edwin Cameron and Didier Fassin and noting that "[t]he news ethnographers were bringing in from the field was hardly encouraging".<sup>492</sup>

Fassin had already revisited his own monograph in the 2013 article, 'A case for critical ethnography: Rethinking the early years of the AIDS epidemic in South Africa'. In the

<sup>491</sup> Jonny Steinberg, 'Re-examining the Early Years of ART in South Africa' (2016), p. 62.

<sup>492</sup> Ibid, p. 61.

article, he relates a scene that took place at the AIDS in Context Conference in Johannesburg in April 2001 in which Nono Simelela, the director of the National AIDS Program, took to the podium directly after the TAC activist Zackie Achmat. Achmat had “launched a virulent attack against the government and its AIDS policy” and “vehemently accused the health ministry of perpetrating a ‘Holocaust against the poor’”.<sup>493</sup> As she responded, Simelela broke down in tears, describing the obstacles she faced in attempting to deliver services through the lop-sided public health infrastructure inherited from the Apartheid regime.

Formulated in sensible and poignant terms, Nono Simelela’s talk echoes the observations I gleaned in the field. Whereas a general tendency among activists and journalists was to assimilate all health officials’ positions to the government’s heterodox stance, I met many physicians, administrators, and public health specialists who did not share their President’s or Minister’s beliefs about the disease and its treatment, but were still expressing doubts about the consequences of developing antiretroviral protocols either to treat patients or even to prevent maternal transmission. By a common form of anachronism when one judges facts ex post, it is often forgotten that, in this period, debates existed on these matters in the international biomedical and political communities.<sup>494</sup>

Perhaps stimulated by the prevalent ‘anachronism’ with which HIV/AIDS in South Africa is now viewed, Fassin explores something that he terms ‘the critical afterlife of ethnography’.<sup>495</sup> By this, he means that the publication of a manuscript represents not an end but a beginning of meaning-making, or perhaps, the end of the author’s control over meaning-making and the beginning of others’ attempts to “transform it in function [according to] ... their understanding or their objectives”. Although accepting of this inevitability, the common

<sup>493</sup> Didier Fassin, ‘A case for critical ethnography’ (2013), p. 121.

<sup>494</sup> Ibid, p. 122.

<sup>495</sup> Ibid, p. 124.

characterisation of HIV/AIDS in <sup>496</sup>South Africa as a mystery, where “the rapid progression of the epidemic remained as perplexing as the odd assertions of the President”, means that texts on HIV/AIDS are – almost by association – easily misunderstood.<sup>497</sup> While both Steinberg's and Fassin's books provide valuable records of the thinking that prevailed during the period in which their research and writing took place and aimed to challenge, they both seem to be on guard against the potential of their texts being judged anachronistically. As such, Fassin wants to reserve “the possibility of [the ethnographer] becoming his own translator”.<sup>498</sup>

The focus of Steinberg's 2016 article reflects not only the benefit of hindsight but also wider shifts within the intellectual environment, specifically the heightened prominence and legitimisation of intersectional scholarship. The original text acknowledged the centrality of masculinity to Sizwe's decision- Steinberg wrote that “Sizwe's failure to test is not simply a tale about health-care services: it is a tale about men”<sup>499</sup> – and the design of the research, in which data was gathered sitting on Sizwe's ‘proverbial shoulder’, produced a narrative predominantly about men's use of health-care services. Paying closer attention to the ways that the *women* of Lusikisiki used the new services that became available to them produces a very different overall picture to the one constructed around the figure of the Everyman. Therefore, he writes, “while suspicion may have been the most vocal of the early responses to the arrival of ART”, as embodied through narratives about Mbeki, Sizwe and Fana Khaba,

<sup>496</sup> Ibid, p. 124.

<sup>497</sup> Ibid, p. 125.

<sup>498</sup> Ibid, p. 125.

<sup>499</sup> Jonny Steinberg, *Three Letter Plague*, p. 375.



"[a] quieter, but no less dramatic response, one embarked upon in disproportionate numbers by young women, was to test for HIV".<sup>500</sup>

Although Steinberg had already noted the phenomenon of the 'missing men' in his original narrative, in the later paper, he gave greater analytic emphasis to the fact that women are more likely to seek medical care than men.<sup>501</sup> Studies have routinely shown this to be the case not just in South Africa but in a range of national contexts, and it is thought to be one factor contributing to the fact that men's life spans are reported as shorter than those of women in every country with reliable health statistics. According to a study carried out by American psychologists Diana Sanchez and Mary Himmelstein, men who subscribe to traditional beliefs about masculinity and patriarchal roles are more likely to ignore or delay seeking help for health problems.<sup>502</sup> In keeping with this general trend, Steinberg reports, "as many as 70 percent of those who began treatment in South Africa in the mid-2000s were women".<sup>503</sup> He expands on his original conclusion thus:

...one response to the arrival of ART in Lusikisiki was to voice deep suspicion, but another was to seek treatment. It is of course quite possible for one person to have both responses, and

<sup>500</sup> Jonny Steinberg, 'Re-examining the early years of ART in South Africa', p. 67.

<sup>501</sup> In the case of HIV/AIDS, [cis-het] women may additionally be more likely to be diagnosed because they are systematically tested for the virus when presenting at a hospital or clinic with a pregnancy, and men come less frequently in contact with (bio)medical institutions. However, the uptake of ARVs (after positive diagnosis) was also higher in women than in men. A study by Nicoli Nattrass, cited by Steinberg in the article, based on data gathered in the 1990s found that South African men were 25% less likely to have visited a public sector clinic in the month previously, and another showed that men were far more likely than women to seek treatment only when they were seriously ill. (Nicoli Nattrass, 'Gender and access to antiretroviral treatment in South Africa', *AIDS, Sexuality and Economic Development*, 14(4), (2008), doi: [10.1080/13545700802266452](https://doi.org/10.1080/13545700802266452))

<sup>502</sup> Diana Sanchez and Mary Himmelstein, 'Masculinity impediments: Internalized masculinity contributes to healthcare avoidance in men and women', *Journal of Health Psychology* (2014), doi: [10.1177/1359105314551623](https://doi.org/10.1177/1359105314551623)

<sup>503</sup> Jonny Steinberg, 'Re-examining the early years of ART in South Africa' (2016), p. 69. This figure also reflects the far higher prevalence of HIV in young women in South Africa, which according to latest statistics is four times higher than their male peers (South African National AIDS Council (SANAC), 'Let Our Actions Count: National Strategic Plan 2017-2022', <[http://sanac.org.za/wp-content/uploads/2017/05/NSP\\_FullDocument\\_FINAL.pdf](http://sanac.org.za/wp-content/uploads/2017/05/NSP_FullDocument_FINAL.pdf)> [Accessed 8th September 2018].

one should not create an impression of a Manichean divide between the sexes. Nonetheless, both of these responses were highly gendered.<sup>504</sup>

In *Three Letter Plague*, Steinberg writes that "[t]he meaning of AIDS in [Sizwe's] life had a good deal more to do with being a son, a prospective husband, and a shopkeeper than living in a district that administered antiretroviral drugs".<sup>505</sup> We ought to understand the former category as being not only about personal concerns but gender-role-specific concerns regarding patriarchal roles and expectations. Close to the end of the book, at a point when the relationship between Steinberg and Sizwe is clearly deeply established, he admits,

"A little bit of me is worried about what other people will think, but that is not the main reason why I won't test".

He cleared his throat, wrapped his fingers tightly together in his lap, and stared ahead.

"If I know I am HIV-positive [...] I will no longer be motivated to do the thing I am doing now [...] I am doing all of this for my children [...] If I have AIDS, then all this work is no longer for my children".<sup>506</sup>

Sizwe remains at the end of the book ambivalent about the possibility of taking ARVs, regardless of whether or not he would test positive, but it becomes clear that for him, HIV/AIDS threatens his ability to provide for and safeguard the future of his family. Having worked so diligently to establish his business, the disease has only the potential to endanger his hard-won social status, making him look weak in front of competitors and undermining his ability to protect his son. Steinberg's chronicling of Sizwe's story supports findings that

<sup>504</sup> Ibid, p. 69.

<sup>505</sup> Jonny Steinberg, *Three Letter Plague*, p. 8.

<sup>506</sup> Jonny Steinberg, *Three Letter Plague*, p. 342-343.

have shown it is not uncommon for men who live with chronic illnesses to struggle with the conventional behavioural codes that underlie their idea(l) of performed masculinity.<sup>507</sup>

For some of the women in Sizwe's village, interestingly, ART had the potential to offer the reverse path, from disempowerment to agency. On initial view, this agency is obscured by both the sickliness of some of the women Steinberg meets who are undergoing treatment, and the unpleasant 'public theatre' that women testing for HIV In Ithanga had to endure, including rumours and insulting speculations about their sexual history and morality. Nevertheless, some of these women were still able to identify and take advantage of an opportunity to "command the new technologies of AIDS treatment and bend them to new purposes".<sup>508</sup> In the support groups that were a mandated part of the ART regime which Steinberg attended, it was apparent that a powerful hierarchy was at work, and those at the top were not just women, but almost invariably young women. There was a handful of men at the meeting [...] to a man, they all spent the meeting in silence. It is difficult to stress the unusualness of such a scene in a place like Lusikisiki.<sup>509</sup>

Not only, however, did the women upend the traditional gender hierarchy, but they also used their new avenue to exercise power along explicitly gender-related lines: "to work upon relations between women and men".<sup>510</sup> Steinberg reports how his own observations in Lusikisiki and other scholarly publications showed a pattern in which peer counsellors would

<sup>507</sup> See for example Karl Kvigne et al, 'Masculinity and strokes: the challenges presented to younger men by chronic illness', *Journal of Gender Studies*, 23(2), (2014), doi: [10.1080/09589236.2013.790797](https://doi.org/10.1080/09589236.2013.790797); Kim Pearson and Barbara Pini, 'Men, Chronic Illness and the Negotiation of Masculinity', in *Disability and Masculinities: Corporeality, Pedagogy and the Critique of Otherness* (London: Palgrave Macmillan, 2017).

<sup>508</sup> Jonny Steinberg, 'Re-examining the early years of ART in South Africa' (2016), p. 70.

<sup>509</sup> Ibid, p. 70-71.

<sup>510</sup> Ibid, p. 72.

strictly instruct other PLWHA that ARVs were fatally incompatible with smoking cigarettes and drinking alcohol, despite not having been trained to do so and the fact that this does not conform with medical guidance. At first mystified, researchers and MSF personnel deduced that "[p]ut simply, drinking, in particular, is constitutive of male sociability. It is one of the things men do together".<sup>511</sup> The women who run the support groups leverage the rare opportunity to manage a public space, in order to serve their needs not only as PLWHA but also as women confronted with systems perpetrating gender inequality.<sup>512</sup> In addition, Steinberg gives credit to the 'test' camp of predominantly women for persuading the 'suspicion' camp that ARVs worked, by courageously (if not necessarily with this intention) "offer[ing] themselves [...] as evidence".<sup>513</sup> The medicine was able to prove its efficacy on and through women's bodies, which were used to "delineate the boundaries of the epidemic, as it were, to show where AIDS ended and other medical problems began".<sup>514</sup> Where public health communication campaigns failed to influence the beliefs of some of the population, South African women can take some credit for their bravery in bridging the gap.

Women are by no means absent from the South African HIV/AIDS story - it is impossible to discount the significance of politicians such as Manto Tshabalala-Msimang and Nono Simelela, activists like Prudence Nobantu Mabele (who sadly passed away in 2017) or even

<sup>511</sup> Ibid, p. 72.

<sup>512</sup> Kathryn A. Rhine's ethnographic study of women's support groups in Northern Nigeria found other ways in which women have appropriated the institution, in this case to facilitate marriage arrangements. Rhine found that the single-sex support groups that she attended, the need for which were stipulated by PEPFAR, attracted women who were looking not for peers and coping techniques – indeed, many women would not disclose their status in the group. Rather, attendees use the space as an arena for matchmaking. As in the South African context, the stated purpose of the support group provides a Trojan horse whereby women can challenge established gender norms and practices, even displacing the original meaning of the group: "Women in the group tell others that they meet in the ARV clinic about the marriages taking place; this compels many to attend meetings" (Kathryn A. Rhine, 'Support Groups, Marriage and the Management of Ambiguity among HIV-Positive Women in Northern Nigeria', *Anthropology Quarterly*, 82(2), (2009), p. 481).

<sup>513</sup> Jonny Steinberg, 'Re-examining the early years of antiretroviral treatment in South Africa', p. 69.

<sup>514</sup> Jonny Steinberg, 'Re-examining the early years of antiretroviral treatment in South Africa', p. 68.

the controversial figures of Olga Visser or Tine van der Maas, in the unfolding of the epidemic. Yet in terms of narrative, the focus of this study, there are fewer works that we can use to shed light on HIV/AIDS in post-Apartheid South Africa. Paradoxically while women may have been more vocal, men have thus continued to dominate public space in the form of published texts, novels and memoirs. One relevant text that is available to us is the journalist Redi Tlhabi's recent biography *Khwezi* (2017), which profiles the woman who accused Jacob Zuma of rape in 2005, and highlights how the intersections of social injustice may contribute to the even lesser audibility of women's experiences. Fezekile Ntsukela Kuzwayo, whose identity became public only after her death, was a daughter of ANC freedom fighters and grew up in exile. During her childhood, *Khwezi* reveals, she had suffered sexual abuse on multiple occasions. The extent of sexual assault in ANC military camps during the anti-Apartheid struggle is an extremely sensitive topic in South Africa, and those who speak or write about it are frequently threatened. In the aftermath of the trial against Zuma, indeed, "Fezekile, an HIV-positive Aids activist, and her mother were hounded out of the country".<sup>515</sup> Tlhabi sees the suffering Kuzwayo experienced during her life as an indictment of South African society:

Her death, at the sunset of Jacob Zuma's presidency, feels like a scathing rebuke of the nation, a damning reminder of its complicity in her trauma and forced exile. *Khwezi is* politics – a symbol of the arduous fight against political and patriarchal power.<sup>516</sup>

The book does not go into issues of HIV treatment or describe Kuzwayo's experiences living with the disease, and it is not entirely possible to unify Steinberg's conclusion that ordinary women were able to use ART to exercise soft power to subdue masculinity within their

<sup>515</sup> Redi Tlhabi, *Khwezi* (2017), p. 3.

<sup>516</sup> Ibid, p. 7.

communities, with Thlabi's questions about the endemic "entitlement of men in positions of power to women's bodies" such as that of *Khwezi*.<sup>517</sup> That is of course part of the point, in that gender and sexuality are bound up with all kinds of social power relations in ways that defy a single narrative of HIV/AIDS. As the gender studies scholar Robert Morrell observes, "[g]ender identities contain silence because they are discursively constructed and policed".<sup>518</sup> In common, nevertheless, is the active effort to surface how patriarchal gender attitudes and the ubiquity – even epidemic - of violence against women and girls in South Africa interface with the HIV/AIDS. Steinberg's re-reading of his data in particular offers a valuable instance of how epistemic disempowerment is - like other forms of injustice and oppression – intersectional.

## Conclusion

In the texts discussed within the chapter, HIV/AIDS indeed comes to reveal truths about the state of post-Apartheid South Africa, most tellingly not - as was the case with the novels discussed in Chapter 4 - in relation to the efficacy of the political nation state, but to unresolved divisions and trauma within the body social. It is notable that the three published texts of life writing – *Khabzela!* (2005), *Three Letter Plague* (2007) and *Khwezi* (2017) - all figure in particular the spectre of masculinity-in-crisis. Steinberg and McGregor portray young men whose traditional roles have been destroyed or dissipated, and who have been left "wounded and more or less ill-equipped to meet the challenges and opportunities that came

<sup>517</sup> Ibid, p. 4.

<sup>518</sup> Robert Morrell, 'Silence, Sexuality and HIV/AIDS in South African Schools', *The Australian Educational Researcher*, 30(1), (2003), p. 48.

rolling in with democracy”.<sup>519</sup> Their feelings of powerlessness are seen to contribute to attitudes towards HIV/AIDS treatment, and indeed can be related back to arguments that Thabo Mbeki’s policies were produced out of reactionary resentment at the Global North’s ability to override his authority.

As we follow the first-person narration of Steinberg and McGregor, and their interactions with the individual subjects of their writing, we witness how cultural blind spots are brought to light through the course of their investigation of the epidemic. In particular, conflicting and rival perspectives about treatment, science and knowledge are surfaced in ways that complement the discussions of earlier chapters; on the workings of dominant groups’ discourses in constructing truths, on the potential for apparent silences to reveal abundant shared knowledge, and on the closure of certain knowledges from those who wield their epistemic privilege less graciously. Both texts remind us how such privileges can act both in service of but also occasionally against research objectives. Indeed, they also remind us of lacunae still to be addressed within the medical humanities, where the dominance of certain foundational conceptions selfhood, patienthood, illness and medical care continue to “exclude important ways of knowing and being”.<sup>520</sup> Taken in sum, the study invites those with power to construct and shape narratives to consider how such work erases or illuminates, dismisses or legitimates the histories, realities and humanity of those impacted by HIV/AIDS and other social phenomena that thrive in environments prone to inequality. As Maria Meneses puts it, “For knowledge to transform itself into solidarity, which guarantees the liberty and equality of each culture, it is necessary to give that “other” culture the status of subject”.<sup>521</sup>

<sup>519</sup> Liz McGregor, *Khabzela* (2014), Location 631, Kindle edition.

<sup>520</sup> Claire Hooker and Estelle Noonan, ‘Medical Humanities as Expressive of Western Culture’ (2011), p. 1.

<sup>521</sup> Maria P. Meneses, ‘When there are no problems, we are healthy, no bad luck, nothing’ (2008), p. 353.





## CHAPTER SIX – EPILOGUE

On the evening of Thursday 17th December 2015, gallery-goers visiting the Tacoma Art Museum in Tacoma, Washington, were confronted with a group of bodies sprawled on the museum floor. Although they may have appeared on first glance to constitute a piece of performance art, the bodies belonged to artists and activists from the Tacoma Action Collective (also abbreviated as TAC) enacting a ‘die-in’ under the slogan and hashtag “Stop Erasing Black People”. The protestors’ intention was to make it impossible for the audience to overlook – using their own corporeal presence as proxies – the African-American people whose lives were affected by AIDS but were not represented in the works on display. The exhibition, entitled *Art AIDS America*, had been billed by its organisers as a comprehensive survey of thirty years of artistic responses to the epidemic in the United States. Ten years in the making - in which time the curators had had to face down numerous obstacles from squeamish art lenders and galleries - it had drawn praise from critics for its boldness of purpose: Shana Nys Dambrot writing in *The Huffington Post* called it “historically salient, stylistically diverse and politically inspirational”, while *The Guardian*’s Jason Farago applauded the Bronx’s hosting of the exhibition for showing how the epidemic motivated “artists of all sexual orientations and genders” to organise and originate in the face of a disease that had “scythed through the American cultural landscape, wiping out a generation of creators”.<sup>522</sup>

<sup>522</sup> Shana Nys Dambrot, ‘Art AIDS America: An Impressive Exhibiton and an Important Curatorial Event’ <[https://www.huffingtonpost.com/shana-nys-dambrot/art-aids-america-an-impre\\_b\\_7777230.html](https://www.huffingtonpost.com/shana-nys-dambrot/art-aids-america-an-impre_b_7777230.html)> [Accessed 31<sup>st</sup> August 2018]; Jason Farago, ‘Art Aids America review – gay artists channel anguish, anger and intimacy’ <<https://www.theguardian.com/artanddesign/2016/aug/19/art-aids-america-review-bronx-museum-gay-artists>> [Accessed 31<sup>st</sup> August 2018].



Figure 6: Protestors taking part in a die-in at the Tacoma Art Museum in December 2015

The TAC's indictment was that the wall of silence had been only partially dismantled, and left otherwise intact, thus obscuring a large segment of those it claimed to represent. In the year of the exhibition, according to the Centre for Disease Control and Prevention, African-Americans accounted for between 40% to 50% of American people living with HIV/AIDS (CDC 2017), yet fewer than 5% of the 107 artists included in the show. Neither is this a recent demographic shift: of the over 600,000 people who have died after being diagnosed with AIDS in the US, almost half (more than 270,000) identified as black: a statistic that reads still starker given that African-Americans make up just 12% of the country's total population. The case of Robert Rayford, the young African-American boy who is one of the first patients known to have presented with symptoms relating to AIDS in the United States and which was cited earlier in this thesis, remains relatively unknown. During subsequent confrontations between the Collective and the Tacoma Art Museum, it became apparent that the curators themselves were unaware of the real history and distribution of the disease in their country. *Art AIDS America* was thus hoisted with its own claim to exhaustiveness,

having marketed itself as presenting “the whole spectrum of artistic responses to AIDS” (Tacoma Art Museum 2015) to a general public that the curators considered to be under-exposed to the epidemic’s reality. Thus, the analytic frame of race revealed the exhibition to be uneasily performing a commemoration that simultaneously functioned as repression.

One of the key conclusions of the thesis is that because HIV/AIDS emerged as a public and political concern at a time when the country was transitioning from the Apartheid regime into a multiracial democracy governed by the ANC, the way that the disease has been narrativised is profoundly bound up with South Africa’s discursive nation-building and self-understanding. Unsurprisingly, given its history, South African discourse has been relentlessly concerned with racial imaginaries in ways which circumscribe narratives of the post-Apartheid era. One such consequence was the intuitively drawn parallel between South African HIV/AIDS and Apartheid, with activists recognising a family resemblance between the oppressions. A tendency to see South Africa as in some ways ‘a place apart’ from the rest of Africa, even ‘sui generis’, however, can produce a form of ‘South African exceptionalism’ that obscures potentially fertile connections between the racial politics within its borders and those fermenting elsewhere.<sup>523</sup> Kirk B. Sides has argued that the United States, in particular, “formed a racial horizon of both precedence and warning for a newly formed South Africa”,<sup>524</sup> and consequently, the two countries in many ways continue to be haunted by the same contradictions. My discussion of the following events from Tacoma, Washington is intended therefore not to re-centre the United States as an originary

<sup>523</sup> Sarah Nuttall, ‘Introduction’ in *Senses of Culture: South African Culture Studies*, ed. by Sarah Nuttall and Cheryl-Ann Michael (Oxford: Oxford University Press, 2000), p. 2; Neil Lazarus has critiqued “the insularity, the provincialism, the self-obsession of so much South African scholarship, including that by South African scholars living abroad, in exile or by choice” (Neil Lazarus, *The Cambridge Companion to Postcolonial Literary Studies* (Cambridge: Cambridge University Press, 2004), p. 610.

<sup>524</sup> Kirk B. Sides, ‘Precedence and Warning’ (2016), p. 222.

site of resistance or signification, but to situate the issues and contestations around narratives of HIV/AIDS in post-Apartheid South Africa in relation to recent shifts in wider, global forms of contemporary progressive politics.

While the TAC's protest around the lack of black artists in the show obviously has overlap with ongoing debates around diversity, the conflict stems from something more than (only) the politics of cultural representation. It stages a more radical, more exigent, more literally vital version of those politics. Writing on the theme of 'AIDS and Memory' for a special issue of *Drain Journal of Contemporary Art and Culture*, Theodore Kerr interpreted the nature of the TAC's protest as emanating not "primarily from living with the human immunodeficiency virus per se [but rather] from a place of being Black, knowing suffering, being deeply impacted by HIV/AIDS their whole lives, and knowing that a failure to be seen reduces life chances".<sup>525</sup> As their slogan suggests, the protest deliberately invoked solidarity with the wider civil rights movement of #BlackLivesMatter which came into being in 2012. Our reading of this incident as an illustration of the links between epistemic injustice and global health injustices is further enriched by Judith Butler's recent work on framing in relation to violence and ethics, where she argues that "[t]he frames through which we apprehend, or indeed, fail to apprehend the lives of others as lost or injured (lose-able or injurable) are politically saturated [and] are themselves operations of power".<sup>526</sup>

While Butler develops the concept, first in her 2004 book *Precarious Life* and then in the 2010 *Frames of War*, in relation to new practices of war after 9/11, the notion of the precarity of certain lives is equally applicable to the concerns expressed by the #BlackLivesMatter

<sup>525</sup> Theodore Kerr, 'AIDS 1969: HIV, History and Race' (2016), no pagination.

<sup>526</sup> Judith Butler, *Frames of War* (2010), p. 1.

movement. Relatedly, the philosopher Luvell Anderson points out that the common misunderstanding of the Black Lives Matter slogan, where it is read exclusively (Only Black Lives Matter) rather than, as intended, inclusively (Black Lives Matter, Too) is produced by “a gap in the collective interpretive resources that unjustly disadvantages the protestors’ ability to express themselves intelligibly, i.e. what is called a hermeneutical injustice”.<sup>527</sup> The speaker is not only misunderstood; she is also made responsible for an unreasonable demand that can be used to further dismiss her as a being with lesser interpretative capacity.

Butler’s analysis sharpens our perspective on the unequal distribution of resources and care, both of which are inevitably finite. The opening premise in *Frames of War* is that:

specific lives cannot be apprehended as injured or lost [because] they are not first apprehended as living. If certain lives do not qualify as lives or are, from the start, not conceivable as lives within certain epistemological frames, then these lives are never lives nor lost in the full sense.<sup>528</sup>

In this extract, a distinction is drawn between lives which can and lives which cannot be “recognized” as embodying the status of subjectivity or personhood and thus warrant protection and preservation. As such, representation in itself is not sufficient, as it may increase visibility but do so without fundamentally altering the status of the represented under the gaze of the powerful – or even anesthetising that gaze to conditions of inequality. Butler points out that “our obligations are precisely to the conditions that make life possible, not to ‘life itself’”,<sup>529</sup> as opposed to the “politics of humanitarianism [which] requires that people remain ill, that they remain dependent [so that] humanitarian action can preserve existence

<sup>527</sup> Luvell Anderson, ‘Epistemic Injustice and the Philosophy of Race’, in *The Routledge Handbook of Epistemic Injustice*, ed. Ian James Kidd, José Melina, Gaile Pohlhaus Jr, (New York: Routledge, 2017), pp. 139-140.

<sup>528</sup> Judith Butler, *Frames of War* (2010), p. 1.

<sup>529</sup> Judith Butler, *Frames of War* (2010), p. 23.

while deferring the very dignity or redemption it seeks”.<sup>530</sup> This shift is especially important in relation to narrative practices because it does not require suffering to be proved or performed in order to trigger action or compassion; it takes us back from empathy to a more fundamental sharing of humanity.

In this sense, Tacoma Action Collective’s protest could be associated with the apparently incongruous actions of Thabo Mbeki in South Africa. There is a commonality in their shared attempts to articulate, through different means and fora, how certain populations in the world are exposed to risk, violence and death at vastly unequal yet, at the same time, apparently orthodox rates. To understand their concerns, the arguments must be read not only as texts of protest – which implicitly juxtapose them against the original, dominant text – but with the autonomy of articulation granted to one in a subject position. Likewise, the recent resurgence of student protest in South Africa through the Rhodes Must Fall and Fees Must Fall movements go beyond their overt (and easily dismissed) demands for the removal of a statue or for universal free education; they represent “a calling to account for how little transformation has been effected, but also a subjecting of this contemporary deficit to a much longer historical analysis in order to see the persistent post-Apartheid structural inequalities of South Africa as not solely an Apartheid narrative but as part of the history of colonization”.<sup>531</sup> In other words, narratives can be truly liberated from silencing when they are given the freedom to construct an agenda rather than to deconstruct a pre-existing one. This indeed might be a basis for a definition of epistemic justice.

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<sup>530</sup> Miriam Ticktin, ‘Medical Humanitarianism in and beyond France: Breaking down or patrolling borders?’ in *Medicine at the Border: The History, Culture and Politics of Global Health*, ed. Alison Bashford (London: Palgrave, 2006), pp. 128 – 131).

<sup>531</sup> Kirk B. Sides, ‘Precedence and Warning’ (2017), p. 236.

This thesis was instigated through the Ego-Media project, a five-year research initiative at King's College London funded by the European Research Council (ERC), which examines the effect of new media - predominantly internet-based forms of social media - on self-presentation and life-writing. On joining the project team, I was introduced to the SHM Foundation, an NGO headquartered in London which had recently run an initiative called Project Khuluma ("talk" in isiZulu) in South Africa. Project Khuluma constituted SMS-based support group, designed to remotely connect young PLWHA for whom attendance at support groups was difficult or in some way undesirable. Lack of support and community, research has shown, can negatively affect the morale of PLWHA and hinder both adherence to medical regimes and recovery, and the intervention was designed to address a lack of psycho-social support that was urgently needed for young people living with HIV/AIDS.<sup>532</sup>

Adolescents had at the time emerged as a key population of concern within the HIV/AIDS field. In 2015, UNICEF had published statistics showing AIDS to be the leading cause of death among adolescents in sub-Saharan Africa; adolescents were also reported to be the only age group among which AIDS-related deaths were rising, rather than getting lower.<sup>533</sup> Project Khuluma belongs to the first generation of mobile-phone based empowerment projects which

<sup>532</sup> Negative health outcomes and poor adherence or compliance with medical treatment have been related to the experience of stigma. Over several studies, the psychologists Margaret E. Kemeny et al found that the "threats to the social self [represented by internalised stigma] elicit a coordinated psychobiological response", which were detrimental to the resilience of patients' health overall. "Consistent with this premise, we found that HIV-specific shame and guilt over a 1-year period predicted immune declines over a 7-year follow-up" (Margaret E. Kemeny et al, 'Shame as the Emotional Response to Threat to the Social Self: Implications for Behaviour, Physiology and Health', *Psychological Inquiry*, 15(2), (2004), p.157 and 159).

<sup>533</sup> UNICEF, 'All In #EndAdolescentAIDS', (2015) [http://www.unaids.org/sites/default/files/media\\_asset/20150217\\_ALL\\_IN\\_brochure.pdf](http://www.unaids.org/sites/default/files/media_asset/20150217_ALL_IN_brochure.pdf) [Accessed 7<sup>th</sup> September 2018]

attempt to engage young people in innovative ways.<sup>534</sup> Public health education programmes have traditionally relied on two modes of outreach: “media (radio, television, movies, billboards, etc). and [...] direct personal communication (discussion groups, individual counselling etc.)”.<sup>535</sup> The former has inherently had to tailor their message to a projected and thus always elusive audience. Project Khuluma’s innovation thus extends beyond the introduction of technological affordances, by bringing together these two strands: the potentiality of mass media with the benefits of intimacy and individualisation. Troubling the notion of the public-private debate, these constructed communities offer insight into new possibilities for conceptualising ideas of belonging, connection and confidentiality/confession. Studies on psychosocial support for adolescent PLWHA have shown that while support group attendance can be helpful, life outside the confines of such a group continues to be beset with challenges.<sup>536</sup>

At the outset of the research project, my aim was to identify the key narratives that circulated around HIV/AIDS and trace ways in which young people used online media to construct selves that resisted, repurposed or reinterpreted these narratives. My hope was to substantiate the secondary data shared with me by the SHM Foundation with interviews, and to draw comparisons between the virtual, disembodied experiences and those in the ‘real world’. However, the ethics requirements of working with young, vulnerable people were beyond the scope of the original design of the project, and I also grew uncomfortable with the idea of

<sup>534</sup> A wide range of projects are clustered under the umbrella terms ‘mHealth’ (mobile health), ‘eHealth’ (electronic health) and ICT4D (international and communication technologies for development), all of which are fast-growing industries.

<sup>535</sup> Martina Drescher, ‘Contextualizing Local Knowledge: Reformulations in HIV/AIDS Prevention in Burkino Faso’, *Language and HIV/AIDS*, ed. by Christina Higgins and Bonnie Norton (Bristol: Multilingual Matters, 2010), p.198.

<sup>536</sup> Webster Mavhu et al, ‘Enhancing Psychosocial Support for HIV Positive Adolescents in Harare, Zimbabwe’, *PLoS ONE* 8(7), (2013), <https://doi.org/10.1371/journal.pone.0070254>



carrying out research in what would within these confines be inevitably superficial, the kind of ‘parachute’ research that a recent Lancet Global Health editorial describes as “parasitic”.<sup>537</sup> I turned instead to looking more closely at the available published narratives that have been discussed during this study. In particular, I became interested in the debate around the culpability of Thabo Mbeki, because the young people who took part in Project Khuluma would have been born exactly during the time in which ART was being denied to South African citizens, including pregnant mothers-to-be. Ultimately, the narratives, novels and life-writings themselves – which I felt first merited further analysis<sup>538</sup> - took on their own life and suggested pressing, discipline-straddling research questions, which I have attempted to answer above. Above all, the intense complexity of the discursive terrain, with its multiple conflicting perspectives, leads me to suggest that the epistemic injustices produced by dominant narratives or ‘prior discourses’ present an under-estimated obstacle to public health and humanitarian aims. Especially as we grow increasingly exposed to divergent views and ideologies, it is crucial that we develop a greater understanding of epistemic diversity both within and outside the academy.

The ever-expanding digital sphere, and its intersections with these existing narratives, is likely to generate a plethora of areas requiring further research. New media and platforms have facilitated ‘ordinary’ people to insert themselves and their concerns into arenas of discourse (such as news agendas) traditionally protected by cultural arbiters and gatekeepers. This has arguably been particularly illuminating in the context of the ‘peripheral’ parts of the

<sup>537</sup> The Lancet Global Health, ‘Closing the door on parachutes and parasites’, The Lancet Global Health, 6 (Jun3 2018).

<sup>538</sup> In his chapter, ‘Illness Narratives’, Neil Vickers concludes that “The representational study of illness now is globally focused and younger scholars especially are producing important work on the representation of health emergencies in the developing world and of indigenous medicine. Even today, much remains to be said about HIV in Africa” (Neil Vickers, ‘Illness Narratives’ (2016), p. 401).

world, which have historically found it more difficult to reach global audiences due to the circumstances of cultural production. At the same time, the fluctuating relations of these technologies to power need to be examined in any consideration of online discourse. Dialectically counterweighting the democratizing capacity of this so-called ‘digital revolution’ are increasingly methodical arrangements to preserve control over ownership and distribution of information.<sup>539</sup> As the editors of the *Routledge Handbook of Epistemic Injustice* (2017) write:

In the era of information and communication, issues of misinformation and miscommunication are more pressing than ever. Who has voice and who doesn’t? Are voices interacting with equal agency and power? In whose terms are they communicating? Who is being understood and who isn’t (and at what cost?) Who is being believed? And who is even being acknowledged and engaged with?<sup>540</sup>

These are questions which this thesis has attempted to keep in mind throughout, building on existing scholarship on postcolonial literature, which engages with the epistemic gaps and injustices whereby narratives from outside of the Global North are under-read, frequently mis-read or read in relation to the Western canon of literature and literary criticism. It has brought these ideas together with medical humanities scholarship, and sought to trace the intersections between biomedicine, (illness) narratives as patient empowerment, and the suppression of ‘Other’ cultures. Against this background of intertwining disciplinary threads,

<sup>539</sup> Writing at the turn of this century, for instance, Martin Hall commented that the infrastructure of the Internet in South Africa itself “seems a repetition of a familiar economy, with a handful of international service providers setting up subsidiaries [...] in Howard Rheingold’s terms ‘homesteaders’ of an ‘electronic frontier’.” (Martin Hall, ‘Digital SA’, in *Senses of Culture: South African Culture Studies*, ed. by Sarah Nuttall and Cheryl-Ann Michael (Oxford: Oxford University Press 2000), p. 461.) Commentators have warned that the ‘digital divide’ between the techno-economically privileged and the “impoverished people (whether in ‘First World’ urban ghettos or ‘Third World’ countries)” could exponentially widen existing disparities of influence. (p. 466).

<sup>540</sup> Ian James Kidd, Jose Medina and Gaile Pohlhaus Jr. ‘Introduction’ in *The Routledge Handbook of Epistemic Injustice* (2017), p. 1.

the thesis revealed ways in which HIV/AIDS as a social phenomenon in South Africa accrued a plethora of conflicting meanings that were rooted in diverse epistemic vantage points. The division produced by the Apartheid system along ethnic lines has left barriers to communal understanding, which are discussed in relation to various texts throughout the thesis. These impediments have an effect not only on our ability to read the narratives which have responded HIV/AIDS but also in practical terms, on the ability of decision-makers and power-holders to apprehend clearly the needs of affected populations and consequently to effectively address them. It is hoped that the new approaches to the intersection between illness, disease and narrative suggested by this thesis will prompt further research, online and offline, and participate in the development of more inclusive methodologies for the study of texts in English and the medical humanities.

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